Development and psychometric testing of a measure of the healthcare experiences of persons with dementia and their caregivers

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Background: Dementia affects many older adults. The Canadian Study of Health and Aging estimates that 8.0% of Canadians aged 65 years or older meet the criteria for dementia.(1) Within the subgroup of individuals aged 85 years or older, the prevalence rate increases to 34.5%.(1) While this is already a substantial proportion of the older adult Canadian population, it is only expected to increase as the Canadian population ages. Persons living with dementia and their caregivers have frequent contact with the healthcare system, yet in spite of this there is still much to be desired with regard to optimizing the healthcare experience for persons living with dementia and their caregivers. Moreover, in order to optimize the experience, it is necessary to be able to measure the experience. To date, no such measure exists. The aim of this study was to develop and test the psychometric properties of a measure of healthcare experience of persons living with dementia and their caregivers.

Methods: The study was conducted in three phases. Phase I was a qualitative systematic review using a thematic synthesis approach. Several electronic databases were searched to identify studies of dementia healthcare experiences in primary and secondary care. Data were abstracted from included studies and analyzed using qualitative analysis software (NVivo 11). The thematic synthesis resulted in the development of a healthcare experiences model, which identified domains for development of a draft experience measure. Phase II sought the feedback of persons living with dementia and caregivers on the developed measure. Participants took part in either individual or focus group interviews (participant choice). All interviews were recorded and transcribed. Inductive content analysis of transcripts was used to identify modifications which should be made to the measure, as well as aspects of the measure that participants recommended remain unchanged. The revised measure underwent psychometric testing in Phase

III. Once again, persons living with dementia and caregivers were recruited to take part. The measure underwent assessment of face validity, content validity, construct validity, internal consistency, and test-retest reliability.

Results: Phase I resulted in a healthcare experiences model. It was hypothesized that the experiences of persons living with dementia and caregivers would be sufficiently different to warrant two different frameworks or models, however the experiences were found to have many commonalities and one model was developed. Consequently, this resulted in the development of one measure for both persons living with dementia and their caregivers. Thirteen persons living with dementia and 16 caregivers participated in individual, dyad, and focus group interviews in Phase II. Based on analysis of their feedback, several changes were made to the measure. These included addressing the topic of driving, improving the clarity of instructions, and making modifications to the wording of a few items. Following these modifications, the measure was ready for Phase III. Eighteen caregivers participated in this phase, though only three persons living with dementia could be recruited. Therefore, psychometric analyses were largely only conducted with data from the caregiver group. The measure was found to have good face validity and content validity. Correlation with a global question on the degree to which healthcare expectations were met showed good construct validity (Spearman correlation coefficient = 0.71). Internal consistency was also high (Cronbach's $\alpha = 0.78$). Test-retest reliability was found to be fair (ICC(2,1) = 0.62).

Conclusions: This three-phase study aimed to develop a measure of healthcare experiences for persons living with dementia and their caregivers. The measure was based on the literature and revised with the input of individuals with lived experience. Caregivers participated in psychometric testing with overall positive results, though further testing is required with persons living with dementia.

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Dedication

I dedicate my dissertation to my children: Thomas, Nicholas, and Julia.

I love all of you more than you will ever know.

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Chapter 1 Introduction and Overview

1.1. Introduction

Dementia affects many older adults. The Canadian Study of Health and Aging estimates that 8.0% of Canadians aged 65 years or older meet the criteria for dementia.(1) Within the subgroup of individuals aged 85 years or older, the prevalence rate increases to 34.5%.(1) While this is already a substantial proportion of the older adult Canadian population, it is only expected to increase as the Canadian population ages. Globally, in 2015 the prevalence of dementia was estimated to be 47.5 million individuals.(2) This number is also expected to increase, rising to 75.6 million by 2030 and nearly tripling to 135.5 million by 2050.(2) Family caregivers play an important role in dementia care for these individuals, resulting in significant physical and psychological effects on the caregivers.(3, 4)

Persons living with dementia and family caregivers find themselves frequently engaging with the healthcare system. In 2014, it was found that persons living with dementia have more than three times as many hospital stays per annum as older adults without dementia.(5) The Health and Retirement Study (2014) found that persons living with dementia were more likely to have potentially preventable hospitalizations and emergency department visits.(5) Persons living with dementia have higher numbers of hospitalizations, stays in skilled nursing facilities, and home care visits than other older adults.(5) Spouses of persons living with dementia were also found to have significantly higher numbers of emergency room visits.(5) In a comparison of caregivers of persons living with dementia to caregivers of older persons living with frailty, caregivers of persons living with dementia were found to have significantly higher rates of stress, depression, poor health, low self-efficacy, and low subjective well-being.(6)

However, in spite of frequent and ongoing engagement with the healthcare system, research shows that there is still much to be desired with regard to optimizing the healthcare experience for persons living with dementia and caregivers. Persons living with dementia and caregivers often experience challenges from early in the diagnostic phase through to the later stages of disease progression.(7, 8) Persons living with dementia and caregivers have expressed difficulty in both the diagnostic process and the timeliness of diagnosis.(7-9) They have also experienced barriers in accessing specialist and community services.(7, 8, 10, 11) Communication both among healthcare providers, and among providers and persons living with dementia and their caregivers, has been demonstrated to significantly influence the healthcare experience.(7, 8) Characteristics of the healthcare providers, such as their knowledge base and attitudes toward persons living with dementia and caregivers, may also impact the healthcare experience.(7, 8, 12) Much of this has been determined through qualitative work utilizing methods such as focus groups or interviews to explore the experiences of persons living with dementia and caregivers. However, to date there appears to be no validated and reliable quantitative measure of the healthcare experiences of persons living with dementia and their caregivers.

This project aimed to address this gap through the development and psychometric testing of a measure of the healthcare experience of community-dwelling persons living with dementia and their caregivers. Such a measure may prove useful for other researchers conducting future studies which may require this type of measure. A validated and reliable measure will allow researchers to determine whether interventions targeting the healthcare experiences of persons living with dementia and caregivers are having the desired effects. In addition to the utility of such a measure in the research realm, it may also have clinical utility. There has been increasing focus in the clinical environment on improving patient experience. Clinicians and healthcare administrators may wish to use the developed measure to evaluate the patient and caregiver experience in quality improvement initiatives or even simply for clinician feedback purposes.

It is important to note and differentiate that the measure assesses experience, rather than satisfaction. Most simply, patient experience can be thought of as a report of what actually transpired in an encounter, versus satisfaction, which would be the patient's assessment of that encounter.(13) Experience, therefore, may be more objective while satisfaction can be highly subjective.(14) Measurement of experience has been suggested to be more helpful for the identification of areas needing improvement.(13) For this reason and due to the lack of existing measures of experience, this project focused on the development of such a measure. The measure was developed in a three-phase approach.

1.2. Overview

Phase I (Chapter 3) entailed a qualitative systematic review of the healthcare experiences of persons living with dementia and their caregivers in primary and secondary care settings. A thematic synthesis methodology was used to conduct the review and develop a model of the healthcare experiences of persons living with dementia and their caregivers. Several electronic research databases were searched using a search strategy developed in consultation with a University of Waterloo health sciences librarian. Search results were deduplicated and titles and abstracts of retrieved records were screened by two reviewers against inclusion and exclusion criteria. Records which met inclusion criteria at the title and abstract level underwent full-text screening, resulting in a final number of 90 included studies. Study characteristics were extracted to be able to provide a context for each study and all studies underwent a quality assessment. Data were analyzed with the aid of qualitative analysis software (NVivo 11) according to the thematic synthesis approach. This phase resulted in a model of the healthcare experiences of persons living with dementia and their caregivers, which was used as the basis for measure development in Phase II.

Phase II (Chapter 4) began with the development of a draft version of the measure. Though it was initially thought that the measure would focus on all aspects of the healthcare experience, deeper analysis through the developed model made it apparent that it would be most appropriate to focus on one stage of this experience. Developing a measure that focuses on all aspects of the experience would result in a measure that is very broad, potentially too lengthy for respondents, and one that might include question items which were not applicable to individuals who had not yet reached a certain stage of the experience. It was found in Phase I that persons living with dementia and caregivers experience common challenges across the healthcare experience stages, however the diagnostic stage is the first time these challenges are encountered. Given the abundance of research in diagnostic experiences and that this is the first step in the dementia healthcare experience, it was decided to focus the measure on assessing the experiences of persons living with dementia and caregivers in receiving a diagnosis of dementia. Draft measure items were developed, using the themes that emerged across stages of the healthcare experience in the Phase I model as measure domains. Feedback on the measure was obtained from persons living with dementia and caregivers through individual, dyad, and focus group interviews, following a semi-structured interview guide. Thirteen persons living with dementia and 16 caregivers participated in the focus groups and interviews. The interviews and focus groups were recorded, transcribed, and analyzed using inductive content analysis. Following each session, I wrote memo notes. The results of the content analysis revealed aspects of the measure that participants liked and those which they recommended be modified, as well as aspects of the measure that appeared to commonly cause confusion. Based on the feedback of persons living with dementia and caregivers, the measure was modified into a version to be tested in Phase III of this project.

Phase III (Chapter 5) consisted of the psychometric testing of the developed measure with persons living with dementia and caregivers. The measure was assessed for face validity, content validity, construct validity, internal consistency, and test-retest reliability. Three persons living with dementia and 18 caregivers participated in Phase III of this project. Participants were asked to rate the suitability of the measure on a 5-point Likert scale in order to assess face validity. Content validity was determined through completion of a content validity matrix. Due to the low number of participants in the persons living with dementia group, the remaining statistical analyses could only be conducted with caregiver group data. Convergent construct validity was assessed by examining the correlation between the degree to which participants' expectations of their healthcare experiences were met with the degree to which they had a positive experience. Face validity, content validity, and construct validity were determined to be good. Internal consistency and test-retest reliability were calculated using the caregiver group data. Internal consistency was found to be high. Test-retest reliability was found to be fair. More detailed results are presented in Chapter 5.

1.3. Reflexive Standpoint

Phases I and II had a predominantly qualitative focus. In conducting qualitative research, it is important for one to reflect and to be aware of how one's own experiences, beliefs, and personal biases may affect the analysis and interpretation of data, ultimately affecting the results of the research. Consequently, I gave careful thought to how my academic, personal, and employment experiences might have contributed to how I viewed and interpreted the healthcare experiences of persons living with dementia and their caregivers.

As a Master’s student in the Health Studies and Gerontology program and currently as a doctoral student in the School of Public Health and Health Systems at the University of Waterloo, I gained significant understanding in how our healthcare system is structured and functions. I have worked to understand the role that this plays in the care of older adults, including those with dementia, and the many challenges the system poses for these individuals. This may have given me an increased awareness of these challenges as I interpreted the available data.

Aside from learning about these challenges through courses and readings, I have witnessed these challenges first hand through volunteer experiences as well as within my own family. Inevitably, particularly in Phase II, I found myself being reminded of experiences similar to those with my grandmother. On more than one occasion, participants asked me if I had any personal experiences with dementia. I shared some of these with participants just as they had shared with me. This may have allowed us to build increased trust and deeper connections, resulting in the participants’ willingness to share their thoughts more openly. Self-disclosure of experiences has also been found to decrease the sense of inequality participants may feel between themselves and the researcher.(15) Additionally, self-disclosure can show respect for participants and some may interpret it as validation of what they have shared.(16) Therefore, this unplanned reciprocal process of sharing of experiences may have improved rapport as well as the level of trust between myself and the participants. Moreover, having a close family member with dementia was added motivation to try to improve the healthcare experiences of persons living with dementia and their caregivers through my research, just as I wish to see these experiences improved for my grandmother and those who participated.

However, it is perhaps my employment experiences which could most affect my analyses and interpretations throughout this project. A few years ago, I worked as a research assistant specifically on a project examining healthcare experiences of persons living with dementia and caregivers in primary care. This project involved the collection and analysis of qualitative data on this topic. Though several years have passed since this project, it is possible that some of the themes and concepts that I became aware of through this work could affect my thought processes and the lens through which I viewed the data I was collecting, analyzing, and interpreting throughout my thesis project. I am also aware that this previous work experience resulted in some expectations I had regarding what I might find, particularly in the literature, which could in turn affect my analysis.

Being conscious of my viewpoints and experiences, I attempted to look at data in an unbiased way though it is inevitable that some aspects of these experiences influence my perspective on the data. To help with this, I journaled my thoughts throughout the project. This allowed me to keep a written record of my perspective and mindset, which makes it possible for myself or others to examine whether and how my thoughts at the time may have played a role in how I interpreted the significant amount of qualitative data analyzed throughout this project. These memo notes became a part of my analysis in Phase II and offered support to some of the themes which emerged from the qualitative participant data. Even in Phase III, which consisted of quantitative analyses, my memo notes helped me to recollect the data collection experience which was valuable when interpreting and explaining the quantitative results. While I attempted to conduct all analyses in an unbiased manner, I acknowledge and am conscious of my perspective and experiences which played a role in shaping the lens through which I view the healthcare experiences of persons living with dementia and caregivers.

Chapter 2 Research Objective and General Methodology

2.1. Research Objectives and Hypotheses

This aim of this project was to produce a measure of the healthcare experiences of persons living with dementia and their caregivers. As previously stated, it is important not to confuse experience with satisfaction. Experience can be defined as a report of what transpired in the healthcare encounter, versus satisfaction, which would be the patient's assessment of that encounter.(13) Most measures designed for persons living with dementia and caregivers tend to focus on measuring depression, behavioural symptoms, burden, or quality of life. This study appears to be the first to develop and test the psychometric properties of a measure of healthcare experience. Moreover, the process of development was carried out in consultation with persons living with dementia and their caregivers. Consultation was completed following a comprehensive review of the literature, which utilized a thematic synthesis methodology to arrive at a healthcare experiences model. This project also undertook the challenge of involving persons living with dementia in psychometric testing to assess the validity and reliability of the developed measure in this population.

The project consisted of three phases, each corresponding to an objective of the study. The objectives and corresponding anticipated results and hypothesis were as follows:

- to conduct a thematic synthesis with the aim of developing a healthcare experiences framework/model that would be utilized to identify possible measure domains;
    - Anticipated result: The dementia healthcare experiences of persons living with dementia and their caregivers will be sufficiently different to warrant the

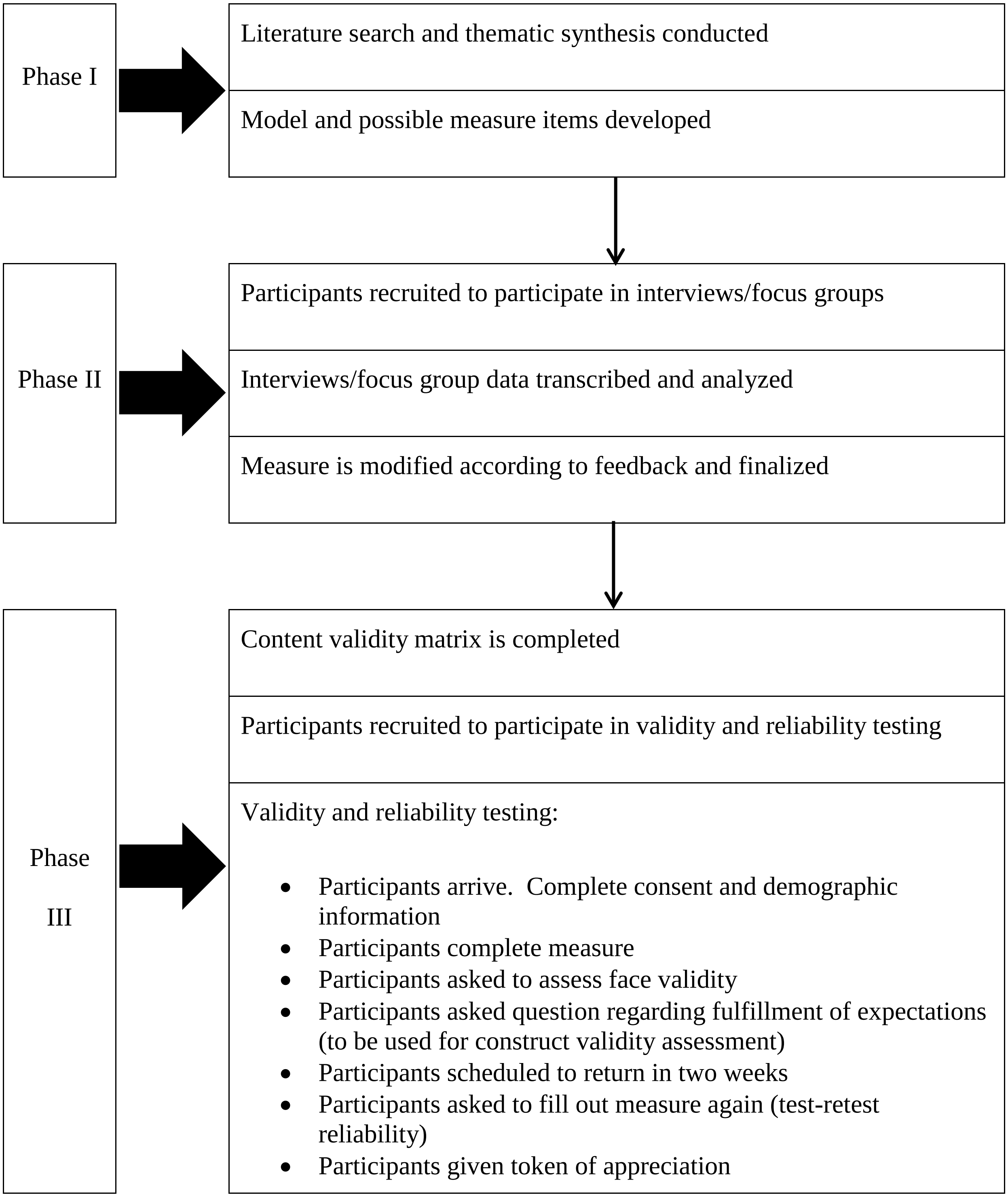
    development of two distinct frameworks/models. Consequently, this will necessitate the development of two distinct measures.

- to consult with persons living with dementia and their caregivers to obtain feedback on the drafted measure based on the developed framework/model to inform measure development;
    - Anticipated result: persons living with dementia and their caregivers will be able to provide valuable feedback on the developed measures through individual, dyad, and focus group interviews. Analysis of feedback will result in modifications and improvements to the measures prior to psychometric testing in the third phase of the project.
- to test the psychometric properties of the developed measures.
    - Hypothesis: The developed measures will demonstrate face validity, content validity, good construct validity, and good test-retest reliability. Internal consistency will also be determined, though it is not expected to be high as the measures will be covering a broad range of aspects of the dementia healthcare experiences.

2.2. General Methodology

As stated, the project consists of three phases. A study flow diagram outlining the major steps of each phase is presented in Figure 1. Detailed methodology for each phase is found in the corresponding chapter of this thesis for each phase: Phase I (Chapter 3); Phase II (Chapter 4); Phase III (Chapter 5). This includes details regarding the thematic synthesis methodology employed in Phase I, as well as details regarding participant recruitment, data collection, and analysis in the remaining two phases. Ethics clearance was received from the University of Waterloo Office of Research Ethics prior to commencement of the project (ORE #: 21692).

Figure 1: Study flow diagram



2.2.1. Theoretical Approach

As there are several phases to this project, an overall theoretical approach has been selected for the interpretation of data and results across the phases as a whole. A constructivist grounded theory approach was found to be most appropriate. Constructivist grounded theory has been employed on several occasions for examining experiences of chronic illness by its main proponent Kathy Charmaz(17-19), as well as by others.

Constructivist grounded theory rejects the existence of an objective reality.(20) This paradigm acknowledges that there are multiple individual realities which are influenced by context.(20) The researcher is thought to be in a position of reconstruction of experience and meaning.(20) Charmaz states that the interaction between the researcher and participants "produces the data, and therefore the meanings that the research observes and defines."(21) She also encourages maintaining the voice of participants in the theoretical outcome, acknowledging that though researchers must be analytical in their writing, it is still necessary to evoke the experiences of participants.(21, 22) Charmaz's approach to constructivist grounded theory aims to provide a balance between maintaining a presence of participants' experiences in the final outcome, with the analysis and interpretations as conceptualized by the researcher.(22) It is suggested to keep participants' words intact in the analysis so as to achieve this balance.(20)

This is the theoretical approach that has been selected for this project. It is well-suited to exploring and analyzing the healthcare experiences of persons living with dementia and their caregivers, as it acknowledges the participants' individual realities shaped by the contexts of their healthcare experiences. Analysis in each phase of the project aimed to stay true to the experiences of persons living with dementia and their caregivers. I was also cognizant of my role in interpreting the experiences of persons living with dementia and their caregivers and acknowledge my part in co-creating and interpreting their realities and experiences as I have presented them. An overall discussion of the results of the phases of the study in relation to the constructivist grounded theory approach is presented in Chapter 6.

Chapter 3 Qualitative Systematic Review/Thematic Synthesis

Abstract

Objective: While research interest in healthcare experiences has grown, to date no measure of experience for persons living with dementia and their caregivers has been developed. Phase I was the first of a three-phase study to develop such a measure. The aim was to conduct a qualitative systematic review resulting in a healthcare experiences framework/model, which could be used to identify potential measure domains.

Methods: The MEDLINE, Embase, PsycINFO, and CINAHL electronic databases were searched to identify relevant articles. Inclusion and exclusion criteria were applied to records screened by two reviewers. Study characteristics, methodologies, and results were abstracted from the included studies. A thematic synthesis was undertaken. The resulting descriptive and analytical themes were used to develop a healthcare experiences framework/model.

Results: The titles and abstracts of 2911 unique citations were screened in duplicate. Full-text review was undertaken for 241 records; 86 articles met inclusion criteria. Agreement was found to be very good between screeners, with Kappas of 0.837 and 0.847 for the title/abstract and full-text screening respectively. An additional four articles were included through focused searching, resulting in a final number of 90 included articles. Thematic synthesis generated 11 descriptive themes, which included relationships with healthcare providers, coordination of care, supports and services, role and identity, and communication, among others. The analytical themes derived from these themes formed the basis of the model.

Conclusions: Elements from the resulting healthcare experiences model can be used to form measure domains and draft measure items for testing in Phase II, resulting in a measure founded in the research literature.

3.1. Introduction

The first phase of this project consists of a comprehensive systematic review of the primary literature on the topic of the healthcare experiences of persons living with dementia and their caregivers in primary and secondary care. The focus is specifically on the qualitative research literature as there has been a substantial amount of research conducted, largely qualitative, pertaining to this topic area. However, few reviews specific to the healthcare experiences of persons living with dementia and their caregivers exist. Of the reviews which exist, most focus on a specific aspect of the dementia healthcare experience. Examples include: barriers and facilitators to assessment and access to dementia care(23); the experience of receiving a diagnosis(24); psychosocial factors which shape persons' living with dementia and caregivers' experience of dementia diagnosis and treatment(25); and discharge and transitional experiences(26). These reviews each looked at varying yet specific aspects of the healthcare experiences of persons living with dementia and their caregivers. All included reviews incorporated the voices of both persons living with dementia and caregivers. Several approaches were used to synthesize the qualitative data, including narrative synthesis, narrative review, thematic synthesis, and meta-ethnography. While barriers and facilitators to positive healthcare experiences were identified, the reviews stopped short of synthesizing the results into a model or framework, with the exception of a meta-ethnographic review by Prorok et al.(7) The review by Prorok and colleagues was the most comprehensive with regard to examining experience; however, this review was still limited to the primary care setting.(7)

The thematic synthesis conducted in Phase I of this project included a broad scope encompassing both primary and secondary care. To date, there is no published review on this topic. The synthesis culminates in a model of the healthcare experiences of persons living with dementia and their caregivers, which may aid in better understanding how individuals who have been diagnosed and caregivers live with dementia. Additionally, it acts as a basis for the development of a measure of the healthcare experiences of persons living with dementia and their caregivers in the phase of the project which follows.

3.2. Methods

3.2.1. Search methods

A search strategy was developed in consultation with a University of Waterloo Health Sciences librarian who has experience in conducting systematic reviews. The MEDLINE, EMBASE, PsycINFO, and CINAHL databases were searched from the start of the coverage period of the database to the search date (August 15, 2016). Focused searching was also conducted following analysis, using keywords in the search engines related to areas that had been identified as less prevalent in the results (ex. palliative dementia healthcare experiences) as well as to seek out contradictory studies. Search terms were determined in consultation with the librarian. The full search strategy for each of the databases is found in Appendix 1. Search terms related to the setting of the healthcare experience, dementia and Alzheimer's disease, and qualitative study methodologies were used. At the recommendation of the librarian, existing search filters for qualitative methodologies were used to maximize the accuracy of the search with regard to these terms.(27-29) A combination of MeSH terms and keyword terms were used. Search results were limited to the English language and deduplicated across the databases. The search results then proceeded to screening against inclusion/exclusion criteria. All records underwent screening by two individuals.

3.2.2. Inclusion and exclusion criteria

The review aimed to identify studies that pertained to the healthcare experiences of persons living with dementia and their caregivers. Caregivers were defined as informal caregivers, such as family or friends of the person living with dementia. Persons living with dementia in included studies must have been community-dwelling. In order to be included in the review, studies must have: been set in primary or secondary care; utilized a qualitative methodology such as focus groups, interviews, or observations; been published in the English language; and reported on experience rather than satisfaction. In instances where a study used a mixed methods approach, the qualitative data only was abstracted and used in the review. Studies which provided some qualitative data regarding a dementia healthcare experience in their results were also included, even if the main objective of the study was not specific to reporting on healthcare experiences. Studies that did not meet the inclusion criteria or that provided data regarding solely the experiences of healthcare providers were excluded from this review. Inclusion and exclusion criteria were applied to the titles and abstracts of studies independently by two raters using the DistillerSR program. The program identified any discrepancies between the raters, which were then resolved through discussion and consensus. Studies which passed title and abstract screening underwent full-text screening once again, independently by two raters using the DistillerSR program. Discrepancies were resolved through discussion and consensus. Inter-rater reliability was assessed and calculated using a Kappa coefficient after both the title/abstract screening and full-text screening stages (prior to the resolution of discrepancies).

3.2.3. Data extraction and analysis

The following information was extracted from all included studies: country, objective, setting, data collection method, analytical approach, and number and type of participants. A quality assessment of each included study was conducted by myself using the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Appendix 2).(30) COREQ consists of a 32 item checklist with items falling in the following categories: personal characteristics, relationship with participants, theoretical framework, participant selection, setting, data collection, data analysis, and reporting.(30) The presence or absence of reporting of each COREQ item was noted for all included studies. Each study was given a score out of 32. This approach to quality assessment in qualitative systematic reviews has been utilized in previous reviews.(7, 31, 32) COREQ scores were not used to determine inclusion or exclusion of a study.

A thematic synthesis approach was used in the analysis of the qualitative data. This approach has been outlined in detail by Thomas et al. (2008) and was developed for the purposes of synthesizing systematic reviews of qualitative research.(33) It has been applied in systematic reviews studying experiences.(31) Thematic synthesis consists of three stages: the coding of text line-by-line, development of descriptive themes, and generation of analytical themes.(33) In the first stage, all results, including quotations and text labelled as results/findings, are entered verbatim into software for qualitative data analysis.(33) Each line of text is then inductively coded according to its meaning and content.(33) Codes were developed as necessary. In this review, this was completed using NVivo 11. In the second stage, codes were reviewed and organized into a hierarchical tree structure, resulting in the generation of the descriptive themes.(33) Once again, this was completed using NVivo 11 as well as by manually organizing the codes, which had been written out on post-it notes, into descriptive themes. Though an independent individual did not review the coding of the data, I did review it as a check of the consistency of the coding. This resulted in the change of one piece of coded text from the diagnostic testing code to diagnostic process code.

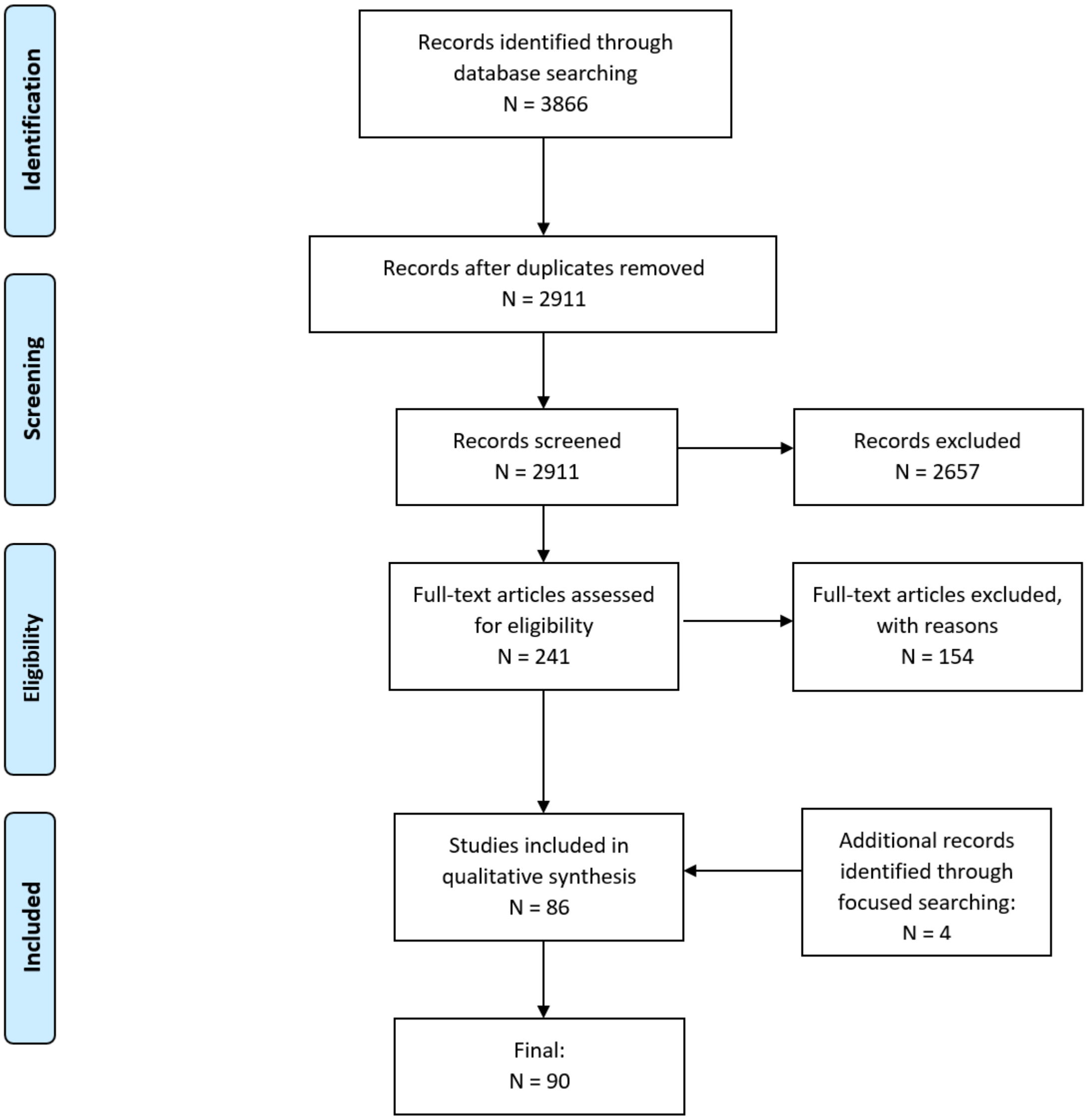
While the first and second stages remain close to the original findings of the primary studies included in a review, in the third stage researchers go beyond these findings to create their own interpretations (analytical themes) to address the research question of their review.(33) The third stage is cyclical with themes developed, reviewed, and modified until the analytical themes are sufficient to describe and explain all of the descriptive themes which were developed.(33) In this study, the analytical themes became the components of a healthcare experiences model which will be presented in the results section of this chapter. The analytical themes and healthcare experiences model were used to guide the development of the measure of healthcare experiences in Phase II of this project.

3.3. Results

3.3.1. Search and study selection results

Figure 2 depicts the PRISMA flow diagram for the search and study selection. The initial search of the MEDLINE, EMBASE, PsycINFO, and CINAHL databases returned 3866 results. Removal of duplicates resulted in 2911 records that proceeded to title and abstract screening. Application of the inclusion and exclusion criteria to these records resulted in the exclusion of 2657 records. The most common reason for exclusion was that the study did not appear to report on the healthcare experiences of persons living with dementia and their caregivers. This was followed by the study not taking place in primary care (care provided by family physicians or general practitioners) or secondary care (care provided by specialists) and finally that the study did not include qualitative data. Full-text review was completed on 241 records, with 154 records being excluded at this stage leaving 86 studies to be included in the qualitative synthesis. Once again, the most common reason for exclusion was not reporting on healthcare experiences of persons living with dementia and caregivers, followed by incorrect setting and finally lack of qualitative data. Four additional studies were added following focused searching. Focused searching entailed key word searches in the previously searched electronic databases to identify any contradictory studies. Moreover, several topic areas were identified in the analyses as ones which could be supplemented with further data. These included the experiences of minorities, palliative care experiences, and positive experiences. Focused searching using key words aimed to identify any further data available specific to these topic areas. Agreement was found to be very good between raters, with Kappa values of 0.837 and 0.847 for title/abstract and full-text screening respectively.

Figure 2: PRISMA flow diagram



It should be noted that in qualitative syntheses, coding of extracted data may be stopped once saturation has been reached. In the case of this synthesis, saturation became apparent after approximately 50 studies had been coded. Coding was done in reverse chronological order, beginning with the most recent studies. However, coding of all 90 studies was completed in case new themes would be generated by older data or in case any child nodes (sub-nodes) of existing parent nodes developed. Two child nodes were identified in the coding of the remaining studies.

3.3.2. Characteristics of included studies

Sample sizes, settings, and methods of data collection of included studies are summarized in Table 1. The 90 included studies had a total of 511 persons living with dementia and 2210 caregivers. It should be noted however that this is an underestimate of the true sample size as some studies did not report sample size. Seven studies included only persons living with dementia as participants, while 54 studies included only caregivers, and 29 studies included both persons living with dementia and caregivers.

In terms of methods of data collection, a majority of the studies employed interviews as a means of obtaining qualitative data (57 studies), followed by 16 studies which used focus groups. Eight studies used both focus groups and interviews, while nine studies used other methods such as observations or written narratives by participants.

With regard to setting, the majority of studies did not specify whether the setting was primary or secondary care. However, though not stated explicitly, the qualitative data made it apparent that the setting was either primary or secondary care. Twenty-three studies included healthcare experiences in primary care, while 12 included experiences in secondary care, and 25 presented healthcare experiences in both primary and secondary care settings.

Finally, slightly more than a third of the studies took place in the United Kingdom, followed by the United States of America (14 studies), Australia (13 studies), and Canada (12 studies). A total of 19 countries were represented by the included studies, with some studies including participants from multiple countries. All of the studies took place in North America, Europe, or Australia, with the exception of three which took place in Asia.

Table 1: Sample sizes, settings, and methods of data collection of included studies

<table>
<tr><td colspan="30">Participants and sample sizes of included studies</td></tr>
<tr><td colspan="6">Studies with persons living with dementia</td><td colspan="6">Studies with caregivers</td><td colspan="6">Studies with both</td><td colspan="6">Total sample size (persons living with dementia)</td><td colspan="6">Total sample size (caregivers)</td></tr>
<tr><td colspan="6">7</td><td colspan="6">54</td><td colspan="6">29</td><td colspan="6">511</td><td colspan="6">2210</td></tr>
<tr><td colspan="30">Methods of data collection of included studies</td></tr>
<tr><td colspan="6"></td><td colspan="6">Focus Groups</td><td colspan="6">Interviews</td><td colspan="6">Both</td><td colspan="6">Other</td></tr>
<tr><td colspan="6">Studies (N)</td><td colspan="6">16</td><td colspan="6">57</td><td colspan="6">8</td><td colspan="6">9</td></tr>
<tr><td colspan="30">Setting of included studies</td></tr>
<tr><td colspan="6"></td><td colspan="6">Primary Care</td><td colspan="6">Secondary Care</td><td colspan="6">Both</td><td colspan="6">Not specified</td></tr>
<tr><td colspan="6">Studies (N)</td><td colspan="6">23</td><td colspan="6">12</td><td colspan="6">25</td><td colspan="6">30</td></tr>
<tr><td colspan="30">Countries where included studies were conducted</td></tr>
<tr><td colspan="10">• United Kingdom: 36
• USA: 14
• Australia: 13
• Canada: 12
• Netherlands: 6
• Belgium: 2</td><td colspan="10">• France: 2
• Germany: 2
• India: 2
• Ireland: 2
• Norway: 2
• Spain: 2</td><td colspan="10">• Sweden: 2
• China: 1
• Estonia: 1
• Finland: 1
• Italy: 1
• Malta: 1
• Poland: 1</td></tr>
</table>

Detailed characteristics of each study, including the objectives and analytical approaches of each study, are presented in Table 3 at the end of this chapter. The studies are presented in the table by year, beginning by most recent, and then sorted alphabetically by first author. This is also the order in which they were analyzed.

3.3.3. Quality of included studies

The COREQ criteria were applied to 85 of the 90 included studies. The presence or absence of reporting of each item was noted for these 85 studies. Assessment of five of the studies using the COREQ criteria was not completed as the methodologies of those studies made the COREQ criteria inapplicable. For example, in one case the qualitative data in the study consisted of a written narrative by the participants.(34) COREQ items 1-8 relate predominantly to the characteristics of the interviewer. In the case of this study, there was no interviewer therefore each of these items would have been marked as not reported. This would make the quality of the study appear lower, as well as lower the overall average COREQ score of the studies, when in fact it would not be fair to judge the study on these criteria.

The average COREQ score was 17.96 out of a possible 32 items. Scores ranged from 5 to 32. Overall, the first domain regarding research team and reflexivity, which included personal characteristics of the researchers and their relationship with participants, was reported most poorly of all of the domains. The reporting sub-domain of Domain 3 (analysis and findings) was overall most commonly reported, with each of the criteria being reported by at least 92% of studies. The area of participant selection was also fairly well reported with the exception of the criterion related to non-participation (reporting of individuals who refused to participate or dropped out), which was only reported by 30.6% of studies. The most poorly reported criterion was whether or not transcripts were returned to participants, with only 3 of 85 studies (3.5%) reporting on this criterion. The most reported criteria were sampling (how participants were selected) and sample size, each reported by 84 of 85 studies (98.8%). Figures 3-5 provide detailed information regarding the number of studies reporting each criterion.

Figure 3: Number of studies reporting criteria within research team and reflexivity domain of COREQ

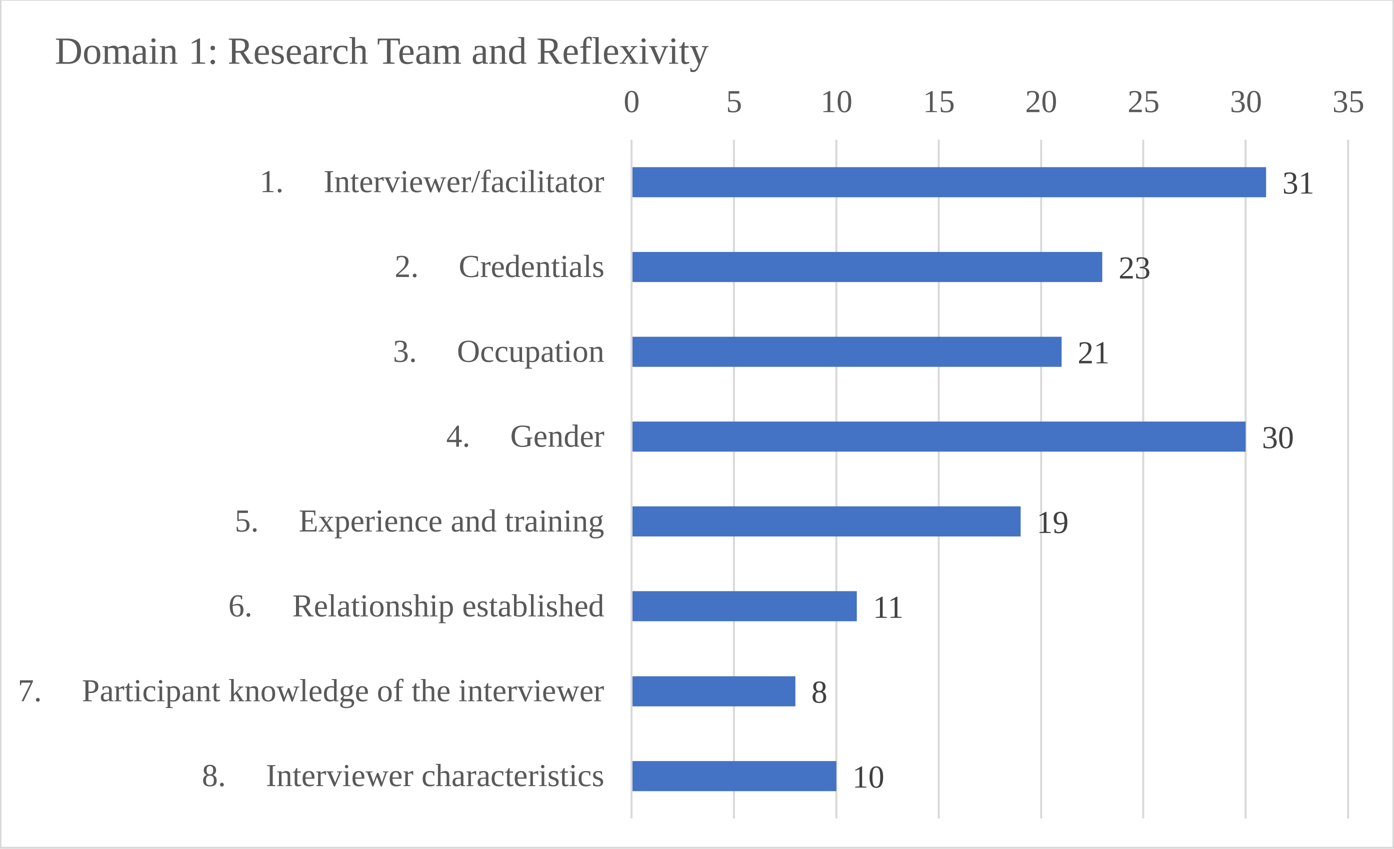


Figure 4: Number of studies reporting criteria within study design domain of COREQ

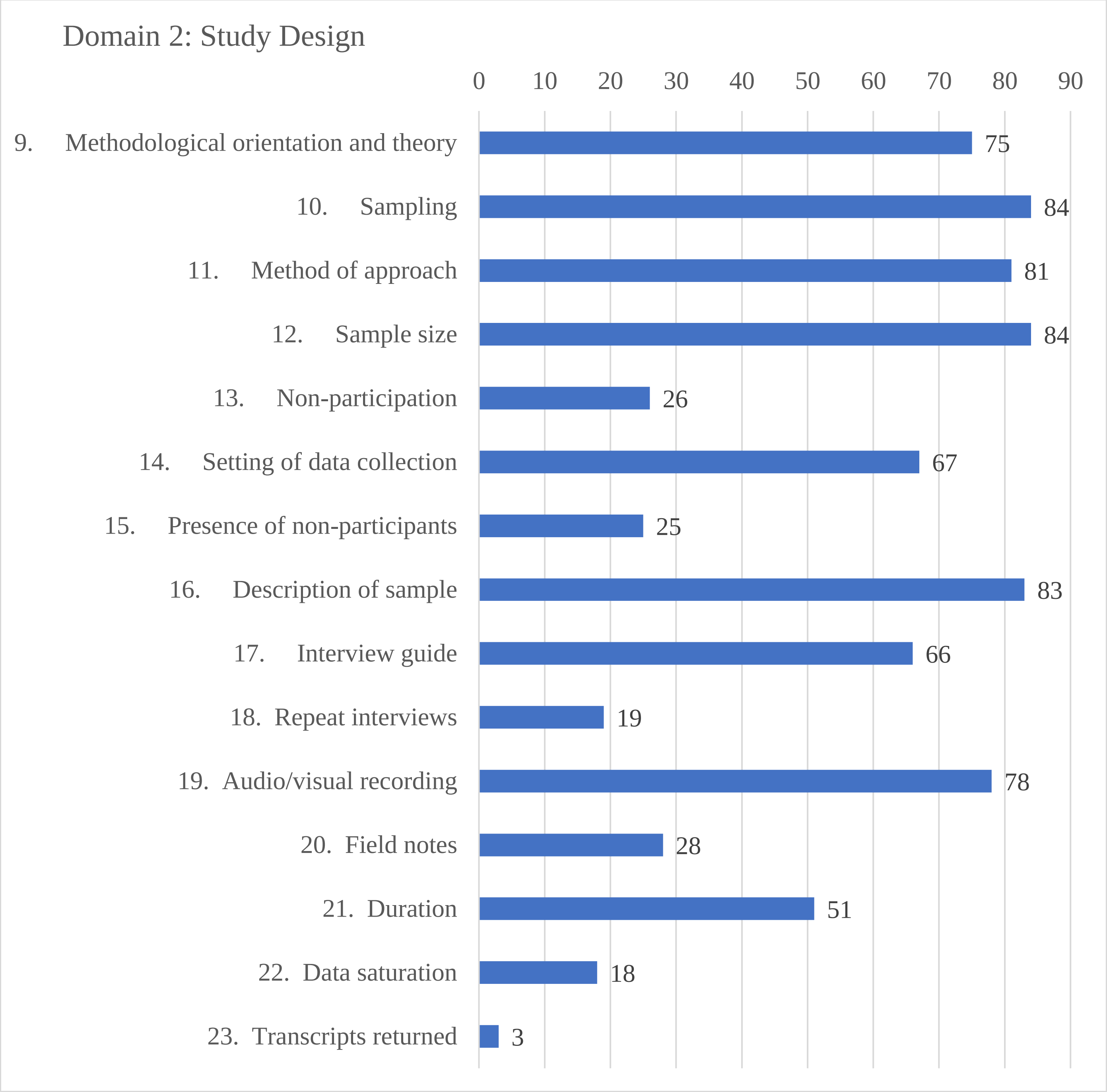
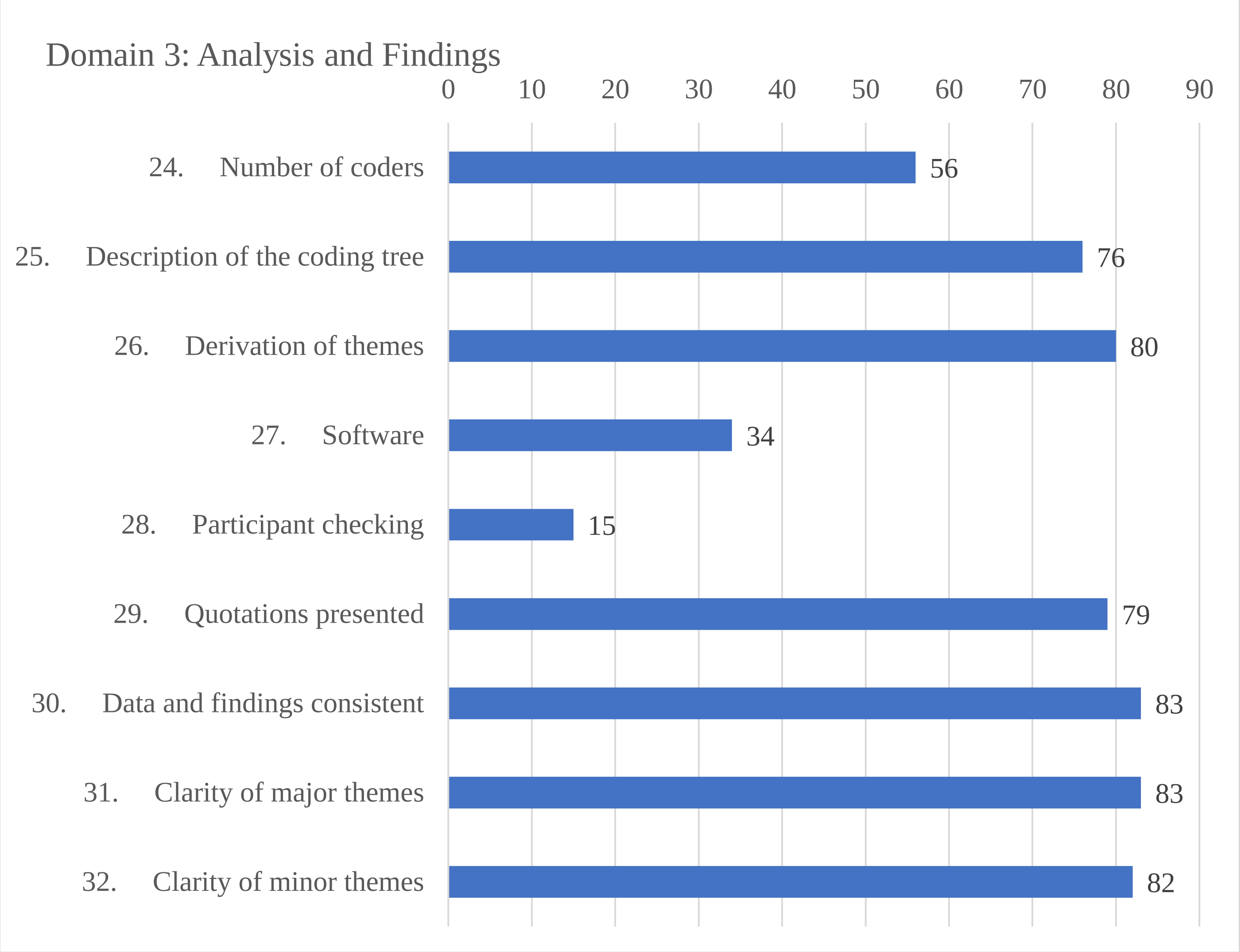


Figure 5: Number of studies reporting criteria within analysis and findings domain of COREQ



3.3.4. Thematic synthesis results: descriptive themes

The results from each of the included studies were coded line-by-line in NVivo, in accordance with the methodology and first of three main steps of a thematic synthesis. In the second step, 11 descriptive themes were generated. A visual representation of the codes and resulting descriptive themes is presented in Figure 6. There were no orphaned data and all data fit within the developed themes. These themes are: diagnosis, time, communication, information, coordination of care, relationship with healthcare provider, supports and services, specialist and team-based care, role and identity, future, and positive experiences. After several cycles of reviewing, refining, and organizing the descriptive themes further into my own interpretations of the data, I arrived at the analytical themes which I organized graphically into a model of the dementia healthcare experience for persons living with dementia and their caregivers. It should be noted that in the proposal stage of this project, I anticipated the generation of two models or frameworks of healthcare experience: one for persons living with dementia and one for caregivers. I anticipated that their experiences may prove to be sufficiently different to warrant separate frameworks or models, however I found the opposite to be the case. I found the experiences to be deeply intertwined with common themes and common key individuals in both the healthcare experiences of persons living with dementia and caregivers. Therefore, one model was developed which encompassed the experiences of both. The analytical themes and model are presented in the following section after more detailed results regarding the descriptive themes.

Figure 6: Visual representation of codes (green) comprising each descriptive theme (yellow)

Theme: Diagnosis

Dimensions: diagnostic process; diagnostic testing; feelings of persons living with dementia and caregivers toward diagnosis

The first descriptive theme of diagnosis represents the diagnostic process, diagnostic testing, and the feelings of persons living with dementia and caregivers toward the diagnosis. Persons living with dementia and caregivers often sought out a diagnosis and care, beginning the diagnostic process. For some individuals this was early on in their healthcare experience, however early diagnosis proved to be more uncommon than common for participants in the included studies. The diagnostic testing experience also did not prove to be a typically positive experience for participants. Participants expressed the need for clearer test results, as there was sometimes confusion as to what the results meant and misunderstanding regarding assessment outcomes.(35)

> "Caregiver: 'After we got the test and I find out that she had fourteen out of thirty…That's it; what does fourteen mean?'"(p. 4) (8)

Reaction to diagnosis varied considerably. Some participants expressed that a diagnosis brought relief and acceptance. Others wished to distance themselves from dementia and their diagnosis.

> "Many caregivers also reported a sense of relief in just getting an answer, regardless of the actual diagnosis. The daughter of a patient diagnosed with AD described the impact of knowing her mother's diagnosis: It just gives a person the peace of mind that yeah, we definitely know what it is and life goes on, I guess. (daughter)" (p.116) (36)

> "For most, the provision of a diagnosis meant an improvement in their situation as they were able to prepare and plan for what lay ahead, such as, 'I felt more at ease knowing what was wrong' and, 'When you know what is wrong, you can do something about it.'"(p.21) (37)

> "Participants continued to refer to others they had known with dementia in a manner that highlighted the differences between those remembered and themselves." (p.27) (35)

Though diagnostic experiences varied, the experiences typically described within this theme were not overwhelmingly positive and identified several areas of the experience needing improvement.

Theme: Time

Dimensions: timeliness of diagnosis and care; amount of time available in visit

The second descriptive theme encompassed all aspects of the healthcare experiences to do with time. This included timeliness of the diagnosis and care, which was mentioned frequently in the included studies. This code appeared in more than a third of included studies. Often times, persons living with dementia and caregivers experienced delays with diagnoses. Caregivers expressed:

> "We had a long, long wait to go to the memory clinic – probably about nine months. You just feel you're battering your head against a brick wall. It was about four years before we finally got the diagnosis. It seemed such a long time, especially as he is so young." (p.222) (38)
>
> and
>
> "The only time it really bothered me is when I noticed things getting a little bit worse and I'm thinking, okay, when is this going to happen? We need to get this checked out, because every other test they did on her for every other possible reason she could be having this memory issue, they all came out just fine. So this was kind of our last resort for answers. So yeah, I was getting a little anxious."(p.113) (36)

It should be noted that there were individuals who contradicted these delays. As one caregiver expressed:

> "It was all dealt with really quickly…I don't think that they could have done much better than they did and it was swift and informative." (p.6) (39)

While a person living with dementia stated:

> “Oh no, that was a… I’m surprised how quick it was [quite quick]” (p.6) (39)

The time theme also encompassed the time a healthcare provider made available for the person living with dementia and their caregiver. Persons living with dementia and caregivers appreciated having healthcare providers who were available and provided sufficient time in the encounter. However, with the exception of a study of a memory clinic where persons living with dementia and caregivers were able to see their healthcare providers for up to an hour and ask any questions they may have had(40), the data supporting this descriptive theme were overwhelmingly negative. Caregivers shared:

> “It’s got to be a little bit more time that still might make you feel that you’ve been listened to perhaps.”(p.5) (8)
>
> “With the doctors, you don’t get the physical time, or really the chance to talk to the doctors. They are all business and that’s it. I’m really disappointed in a way, I think they could have taken a little more time and done a little bit more for her.” (p.13) (41)
>
> “The doctor hasn’t got time ... is a busy man.” (p.26) (35)
>
> “The doctor...does what he can to help...the only problem is he is so damn busy.” (p.187) (10)

The descriptive theme of time proved to be an important part of the healthcare experience, which appeared throughout the experience from the time individuals sought a diagnosis through to the time available to persons living with dementia and caregivers throughout their care.

Theme: Communication

Dimensions: Delivery and communication of diagnosis; communication between healthcare providers, persons living with dementia, and caregivers; quality of communication (or lack thereof)

Similar to the descriptive theme of time, communication was demonstrated to play a substantial role throughout the healthcare experiences of persons living with dementia and their caregivers. Communication of diagnosis in particularly was heavily discussed. Persons living with dementia and caregivers expressed that much could be improved with regard to the delivery and communication of the diagnosis. One caregiver stated:

> "Really she (person with dementia) was never sat down and told, "By the way, this is what we found and this is what it may mean and with you and your family you might have to work on some of these areas." (p.4) (8)

This was confirmed by several other caregivers.

> "One caregiver stated how she would have liked for the PCP to sit down and explain the diagnosis and steps following diagnosis with both herself and her mother (the person living with dementia)."(p.3) (8)
>
> "Not enough explanation was given...He just said that this illness could not be cured, and he prescribed several kinds of medicines" (p.141) (42)
>
> "Yes, they should have [explained the diagnosis to the patient]...I think it's important to explain to her."(p.141) (42)

One person living with dementia shared particularly strong sentiments regarding the delivery of her diagnosis:

> "It was not really so much the fact of having that diagnosis, it was the way that diagnosis, the information was delivered to me…I felt like I was a criminal in the dark…like I had done something terribly wrong and that's one of the worst things that I've encountered since my diagnosis. It felt punitive." (p.4) (8)

In another study, persons living with dementia offered the characteristics they valued when a clinician was delivering the diagnosis:

> "Three patients considered that certain attributes were required of the clinician when giving the diagnosis – "the doctor needs to be supportive," "a good listener," "easy to understand." (p.1267) (43)

In addition to the communication of a diagnosis to persons living with dementia and their caregivers, the literature also focused on communication in general between healthcare providers and persons living with dementia and caregivers. Participants in studies stressed the importance of both verbal and non-verbal communication(8), being engaged in discussions(8, 44, 45), and feeling recognized and listened to(46). One caregiver stated:

> “You don’t have to be mean or blunt…but somewhere between blunt and no information, there’s like some kind of area where you can say something other than, ‘Your mother shouldn’t be alone and she shouldn’t be looking after her money.’”(p.3) (8)

Caregivers in one study stated that their experiences could be improved through better communication not only with regard to sensitive topics such as diagnosis, but also practical aspects of the experience such as timing of follow-up appointments.(47) This was echoed by a caregiver participant in another study:

> “Nobody ever calls me back to tell me that everything’s fine, or that they’ve done this or that... no one ever calls me back to communicate what has happened. There’s never any follow up on anything unless I make a point of going and talking to someone. I find that very difficult.” (p.106) (48)

Authors of yet another study wrote that “Communication difficulties were the source of much frustration and seemed to extend to all areas of interaction with healthcare professionals and social services.” (p.24) (37) These data, along with those presented earlier in support of the communication theme, demonstrate that persons living with dementia and caregivers feel that communication could be improved throughout the stages of their healthcare experiences.

Theme: Information

Dimensions: information needs congruent to stage of disease; breadth of information needed

Information was also a key descriptive theme which emerged from the data. In particular, information needs of persons living with dementia and their caregivers were heavily discussed. Information needs was the most prevalent code; it was used more than 20% more than the second-most prevalent code. Overall, many persons living with dementia and caregivers felt that their information needs were not met. The scope of the information needs ranged across the entire spectrum of dementia progression and related to a variety of topics. For example, information needs related to diagnosis were frequently discussed.

> "The vast majority of the patients reported having received little or no information from health professionals about their diagnosis." (p. 478) (47)

> "Many participants reported feeling they had not been given a diagnosis or sufficient information about their condition or potential treatment options." (p.478) (47)

> "Caregiver: 'They know the information so well themselves. They do it every day but they don't realize that you don't know.' Caregiver: 'I didn't even know what dementia was.'"(p.4) (8)

Progressing from the diagnostic stage, the information needs of persons living with dementia and caregivers continued as they learned to live with the diagnosis and the changes it brought to their lives. The focus of the information needs shifted from information about the disease to how to manage it and how to slow its progression.

> "Many also wanted information about how to prevent further deterioration in memory, and quite a number of participants stated that they would be interested in information about what they could do to preserve their cognitive function." (p.478) (47)

> "Many expressed an interest in receiving information about potential therapeutic options (both pharmacological and non-pharmacological) for their cognitive problems. Other topics that participants reported wanting information about included their likely prognosis and common causes of cognitive impairment." (p.478) (47)

> "Many patients reported that they would like to be given strategies to cope with their symptoms, e.g. "hints" and "tips" about how best to deal with their limitations." (p.478) (47)

> "Caregivers expressed a need for information about what to expect in the way of disease progression and how to handle behavioral changes that are a part of the disease process." (p.61) (49)

> "In particular, none had received advice regarding management of behavioural problems, which for many was the focus of their concerns. Many caregivers expressed a wish to know more about the disease and its management." (p.4) (50)

Information needs continued even in the final stages of the dementia journey.

> "And at what point do you have to put her in long-term care or something? Yeah, so I guess more information and a little bit of guidance." (p.115) (36)

> "Participants' accounts also suggest there is a need for greater information about and preparation for the dying process." (p.335) (51)

The topics about which persons living with dementia and caregivers expressed need for greater information also varied considerably. They ranged from information regarding health services, basic information regarding paperwork and forms, to a variety of medical-related topics.

> "The need for consistent, reliable and current information about dementia and health services available to both care recipients and caregivers was mentioned by many caregivers." (p.107) (48)

> "Caregivers especially expressed a desire for 'simple advice' to help them deal with the difficulties they experienced. This could include filling in forms, finding out about services that were available, and looking at the 'hurdles' they might face." (p.91) (52)

> "Safety issues such as falling, handling drugs, the danger of gas stoves, and arranging aids and adaptations to the home were key areas where information was needed, although not all caregivers requested it." (p.272) (53)

> "Not only did the caregivers desire information about Alzheimer's, they needed assistance in better understanding some of the dangers, illnesses, and concerns that often accompany Alzheimer's. These included depression, malnutrition, irregular sleeping patterns, wandering, falls, incontinence, and pneumonia." (p.14) (41)

Keady et al. provided a detailed account of carers' information needs in their study, which also summarizes well what emerged overall within the descriptive theme of information.

> "A structured and systematic approach to information was the exception, rather than the rule. What carers wanted was information tailored to their needs, rather than a blanket approach, or worse still, no information at all. None of the carers in the questionnaire group had been given any written information on dementia when they were told the diagnosis, and subsequently they had to find out what they wanted for themselves. This, however, often did not meet their needs:

> ‘I would like to receive more personalized information. The only written material I have ever received is from the Alzheimer’s Disease Society and there was just so much of it, it put me off reading it. I don’t want to know about brain tissue donation just yet, and there is only so much you can remember from a conversation.’
>
> What carers in both groups wanted was written and verbal information on the availability of support, an explanation of the diagnosis and practical coping skills. What became apparent from the data was that during the immediate post-diagnostic phase, information was a central plank in the process of adaptation and helped to lay the foundation for future successful caring.” (p.36) (54)

A caregiver in a different study summarized one of the key challenges related to information rather succinctly:

> “If you don’t ask the questions, you don’t get the information. However, you don’t know the questions to ask so how can you get the information?” (p.243) (55)

Given the breadth of topics mentioned by persons living with dementia and caregivers as well as the continued importance placed on information throughout all stages of the dementia journey, it is evident that this was a key descriptive theme identified within the healthcare experiences of persons living with dementia and their caregivers.

Theme: Coordination of care

Dimensions: primary care provider as first point of contact; lack of role clarity; ability of healthcare providers to work together influences whether persons living with dementia and caregivers have positive or negative experiences

Several codes fell into the next descriptive theme of coordination of care. Coordination of care entailed the interactions between the healthcare providers involved in the persons living with dementia and caregivers’ healthcare experiences. Most often, it was stated that the first interaction was with the primary care provider. For example:

> "It's the most appropriate place that she's there attached to the GP [general practitioner] and let's face it I can't get any service for mum or any care unless I go through that point." (p.4) (56)

> "Therefore, unsurprisingly, for those proactively seeking help for memory problems, primary care was the first port of call." (p.60) (57)

> "In every case, family physicians were the first health professionals to be contacted." (p.376) (58)

Once the primary care provider was involved, this typically led to the involvement of other healthcare professionals often through referrals to providers and services. However, it was not always clear to persons living with dementia and their caregivers what the roles of the individuals involved in their care was.

> "People with dementia and family carers also identified the lack of clear lines of responsibility among care providers." (p.5) (59)

> "Several carers were also uncertain of the differences in roles between the district nurse and the health visitor for the elderly. As one adult child carer explained: 'I want to know what you do. I don't understand your fancy titles.'
> The clear implication here is that service providers need to explicate their roles, both to each other and to those in receipt of their services if optimum benefit is to be obtained." (p.36) (60)

> "When I've mentioned it to our own GP [general practitioner] or a GP down there, erm, I've just said about the tablets and that, 'Oh you'll, have to see about [the memory clinic]. . . . They feel that . . . Alzheimer's is to do with [the memory clinic].' That's the impression I get from them. But it's a sort of division. (Caregiver C)" (p.91) (52)

In addition to the challenges created by lack of role clarity, persons living with dementia and caregivers experienced significant obstacles and stress in their experiences when it came to healthcare providers working together. The need for better coordination was evident, as it appeared that in several cases the onus was on the persons living with dementia and/or caregiver to facilitate the coordination of care.

> “There should’ve been a social worker involved, but they weren’t co-ordinated; one didn’t know what the other was doing ... Now there’s four people involved, but one doesn’t seem to know what the other’s doing.”(p.242) (55)

> “They should be working in closer like, err, well it should be a two-way thing: community and the service provider and the carer and the person that’s being cared for and the whole family in general, that sort of thing gotta be sit down and worked out together. (Carer 14)” (p.6) (61)

> “Having an identified named nurse, contact person or a key coordinator was identified as a way of achieving the goal of not having to communicate with multiple people.”(p.1412) (46)

> “These poor communication mechanisms meant that the services often relied on unpaid carers to ensure that the appropriate information was passed between the services, and that appointments were arranged and attended by a person with dementia.” (p.1110) (62)

> “I think it took that length of time to get there because of the fact that the services were not joined up. If each of them had been talking to one another, I think things would have moved a bit quicker.” (p.1111) (62)

Conversely, there were occasions presented in the literature where healthcare providers worked together collaboratively, contributing to positive healthcare experiences for the persons living with dementia, caregivers, as well as positive work experiences for the healthcare providers themselves.

> “The ideal was when the GP and pharmacist would work collaboratively to help them to coordinate this task.” (referring to medication management) (p.742) (63)

> “The trust and support evident in relations between team members enabled the nurse prescriber to work in a holistic way but also in the knowledge that back-up and complementary support was on tap for service users and family carers.” (p.147) (40)

> “For me the greatest relief was actually that I had a single point of contact and not an administrative one like at the CIZ [care assessment center] or wherever, but really someone who came to my mother and who I could go to with questions.” (p.273) (53)

A carer referring to effective coordination of care as “the greatest relief” underscores the significance of this descriptive theme in the healthcare experiences of persons living with dementia and their caregivers.

Theme: Specialist care and team-based care

Dimensions: appreciation of specialist care; positive experiences with healthcare providers other than physicians

Experiences with specialist and in team-based care emerged as another descriptive theme within the coded data. Contrary to many of the previously described negative experiences which pertained largely to experiences with family physicians, experiences with specialist and other types of healthcare providers were found to be more positive. Many persons living with dementia and caregivers appreciated the expertise they felt these individuals possessed.

> “Access to specialized clinics generally brought a certain degree of satisfaction: At this point, caregivers recognized that they were in good hands, and it was at last possible to place a label on the problem.” (p.347) (64)

> “Caregivers were especially appreciative of the proactive efforts of geriatricians to review their relative’s medications and in many cases reduce the number of prescribed medications. They expressed relief at having to manage fewer daily medications for their relatives.” (p.55) (65)

These positive experiences were not just specific to physician specialists, but other healthcare providers involved in team-based care. Persons living with dementia and caregivers expressed positive experiences with other healthcare providers such as nurses and social workers. Some individuals perceived these healthcare providers as being more available and having more time to talk than their physician healthcare providers.

> “Another carer was comfortable with the NP because she specialized in dementia services and care and was not a general nurse.” (p.147) (40)

> “She (social worker) says you can call me day and night. That accessibility is important and that they know you as a person and that they know the situation. They supervise the situation and discuss whether you are still able to handle by yourself.” (p.1411) (46)

> “It’s a great improvement. It’s a great step forward without a doubt. I don’t know why you have to go the GP to get a repeat prescription for three months, and then see him again just to get another. It is time consuming for him and inconvenient for me. It is much easier if you just see the nurse.” (p.148) (40)

> “A valued feature of the NP service offered to service users and family carers was the ability to telephone the nurse prescriber if they had any queries or problems.” (p.151) (40)

The expertise and perceived availability of other healthcare providers was valued by persons living with dementia and caregivers in the literature. Many of these individuals had waited significant periods of time for access to this specialized care which may have also made them more appreciative once it was received.

Theme: Relationship with healthcare provider

Dimensions: working together; respect, dignity, and trust

The descriptive theme of relationship with healthcare provider played a significant role in how individuals perceived their healthcare experience. Just as healthcare providers working collaboratively with one another generally resulted in positive experiences, this was also the case when the providers worked together with the persons living with dementia and caregivers themselves.

> “The hallmark of the smooth pathway to diagnosis narratives is that, for the most part, families and a network of formal healthcare providers appear to work well together to establish a diagnosis with which families feel comfortable and satisfied.” (p.139) (42)

> “They (caregivers) also spoke with their pharmacist to alert them of their relative’s dementia and cognitive decline. They worked closely with them to keep track of prescriptions and manage dispensing of extra prescriptions, often obtained when the

> care recipient visited doctors other than their regular doctor, and over the counter medications:
> Fortunately we had a relationship with the pharmacist and she'd ring and say 'look he's come in with this particular script' and we'd say 'no, you don't fill it." (p.55) (65)

How the healthcare provider treated the persons living with dementia and caregivers also played an important part of the relationship with the healthcare provider. Naturally, persons living with dementia and caregivers appreciated empathy, respect, dignity, and the development of trust in the relationship.

> "Participants described the need for primary care providers to communicate with empathy and a caring demeanour." (p.3) (8)

> "The participants emphasized that PwD and the informal caregiver should be addressed as experts on their life situation and this happened when care was at its best." (p.1410) (46)

> "My first GP wrote me off, not giving me the dignity of answering questions, not proffering any advice." (p.281) (66)

> "I have had nurses who have taken my blood pressure without speaking or acknowledging me: all sly hidden ways of taking away my dignity." (p.281) (66)

> "Building this trust between person with dementia and service providers would 'take time' to 'talk in confidence'. The importance of communication in building trust was expressed: 'trust factor is built up and maybe he or she would open up and talking cushions the blow'." (p.711) (67)

A good relationship with the healthcare provider often helped facilitate care. Persons living with dementia and caregivers with good relationships with their healthcare providers felt that their provider truly knew them and that they could count on them in difficult times. However, there are situations where a strong relationship can also complicate care. For example, one study described an instance where a good relationship made it challenging to take away the drivers' licenses of persons living with dementia.

> "Rural family physicians who often had a long-standing relationship with the PWD, occasionally preferred to refer the PWD to a geriatrician to conduct the assessment and make this difficult decision." (p.7) (68)

The physicians did not wish to jeopardize their relationships with their patients. These types of instances are more exceptions rather than common occurrences. For the most part, good relationships between healthcare providers and persons living with dementia and caregivers served to positively impact the healthcare experience.

Theme: Supports and services

Dimensions: making connections; need for system navigator; supports and services tailored to needs

The next descriptive theme of supports and services includes persons living with dementia and caregivers' experiences in connecting with services through their healthcare providers as well as the support they feel they may or may not have received from these providers. The Alzheimer society was one common service which participants had varied experiences in accessing. Some individuals were referred by their physicians at the time of diagnosis and found this to be very helpful, while others did not receive referrals

> "My doctor suggested I contact the Alzheimer Society and I did and the rest all came into place after I was there." (p.5) (8)

> "Moreover, several caregivers did not receive referrals to the Alzheimer Society upon diagnosis, which they acknowledge would have allowed them to 'cope better.'" (p.5) (8)

Support available through Alzheimer Society services had the potential to fill a gap identified by persons living with dementia and caregivers; that being the role of a system navigator or central person to help with identifying and accessing available supports and services.

> "Caregiver: 'It's almost as if once a diagnosis is made, if it's communicated, there should be a person, it may not be the physician because of time, there should be a person to sit down with the diagnosed person and the family and has those resource

> list and just says ‘We’re going to bridge the gap and you need to go.’ You know that little step is missing.”
> Caregiver: “I’m dying for somebody to say to me, some sort of mechanism where we can get into the system.” (p.4) (8)

> “One spouse described this process as follows: ‘You’re basically up against a blank wall. There’s no doors that say try me. There’s nothing out there to act as a guidepost. You’re in a wilderness and there are no signposts.’” (p.179) (45)

> “Instead of a number of professionals and means of entry to help and support, a need of single point and contact/case manager.” (p.1410) (46)

> “PWD and their caregivers identified the need for a single contact person to facilitate system navigation and shared their experiences of prolonged paths to resources and supports.” (p.5) (8)

> “The need for a single point of access to information and service coordination was expressed as a means to manage these challenges and to facilitate more efficient and effective service delivery.” (p.1111) (62)

Persons living with dementia and caregivers also expressed the importance of obtaining support from the healthcare providers involved in their healthcare experiences, in addition to informal support from family and friends.

> “The need for emotional support, for instance in terms of counselling, should be recognized by professionals. A sister said: Now, when she is admitted to a nursing home, I need someone to talk to. Someone who will listen.” (p.1411) (46)

> “There was a sense from the interviews that the focus in both primary and secondary care models is on diagnosis with little in the way of robust post diagnostic support, either for the patient or carer:
> “I had rather hoped that we might get some advice but you know in January I must say it didn’t seem likely” [SC, C].
> “Well I don’t think we were given any support really no…I would have liked to have been told about the various groups that are there to help” [SC, C].” (p.9) (39)

Persons living with dementia and caregivers stated their preferences for supports and services which were tailored to their specific needs and situations.

> “Planning care and support for people with dementia required addressing the changing needs of service users, as well as personal preferences.” (p.240) (55)

> "An important point was raised by a couple whose preference for not engaging in community events did not change following a diagnosis of dementia. Therefore, available support such as day centres and carer groups were not appropriate for them." (p.240) (55)

> "Participants wanted the professionals to be flexible and creative, able to imagine and empathize with the perspectives of the PwD and informal caregiver and to provide the individualized care and interventions needed." (p.1413) (46)

> "The appraisal of support as insufficient occurred when men received aid from agencies, professionals, family, or friends, but the support was inadequate to meet their particular needs." (p.187) (45)

> "Carers have a need for information about services available to them in the community. But this information is most helpful when provided by an experienced worker who can understand the carer's situation and help them navigate their way through this information." (p.335) (51)

Supports and services were found to play a critical role in the dementia journey for persons living with dementia and caregivers. The opportunity to make appropriate linkages to these resources was identified as part of the healthcare experience for persons living with dementia and caregivers, often following the diagnostic phase.

Theme: Role and identity

Dimensions: importance of maintaining current lifestyle; preservation of self-worth and identity; evolution of roles

A diagnosis of dementia often and almost unavoidably brought about change in the lives of persons living with dementia and caregivers. As part of this change, persons living with dementia and caregivers found themselves contemplating their evolving roles and their personal identities. The descriptive theme of role and identity included concepts such as the importance of maintaining current lifestyle and preservation of self-worth and identity.

> "Overall, participants were keen to maintain their current lifestyle and to continue engaging in activities that supported their identities and self-worth." (p.28) (35)

> “Acceptance of dementia diagnosis did not diminish the need to maintain self-worth through accomplishing tasks.” (p.38) (35)

In spite of persons living with dementia and caregivers valuing the importance of maintaining as much of their lifestyles as possible, there was no denying a change in roles. This was often challenging to adapt to and in some cases was perpetuated by the continued stigma surround a diagnosis. Individuals experienced challenges sharing a diagnosis and the role changes that came with it.

> “Findings about the constraints of diagnosis reveal a shared sense of stigma and futility about dementia.” (p.185) (24)
>
> “‘I admitted it in front of my GP, but I couldn’t mention it to my family and friends; that was difficult you know’. He discussed ‘shame’ and ‘stigma’ in revealing mental health difficulties to his family and community.” (p.710) (67)
>
> “Evolving role from husband or wife, to caregiver was slow.” (p.27) (35)
>
> “Dementia obliged caregivers to take on different roles in the relationship with the care recipient. This change in roles was difficult to adapt to.” (p.933) (69)

Maintenance of role and identity is a significant part of the dementia journey for persons living with dementia and caregivers despite not being heavily discussed in the available literature. In relation to healthcare experiences, it is important for care providers to be aware of this theme and to support individuals as their roles evolve and they try to preserve their identity.

Theme: Future

Dimensions: lack of hope; planning for the future

Once diagnosed, many individuals’ thoughts turn towards the next descriptive theme of the future. Though individuals are aware that there is no cure, the exact progression and trajectory of the disease can vary. Some individuals did not express much hope for their futures.

> "Each day is worse than the day before. Things aren't getting better, they are getting worse." (p.152) (40)
>
> "Some participants with mild cognitive impairment or dementia, and/or their carers refused treatment or assistance believing it was futile. One person with dementia summed up the futility he felt, saying:
> ... you can go see the Pope himself, or anybody else, and you won't get anywhere." (p.27) (35)

In some cases, this was perpetuated by the healthcare provider.

> "Basically told family Mum would just get worse, that she had no treatment that would help. No info given to family." (p.363) (70)
>
> "GP was nice enough but gave impression that there was nothing he could do for mother." (p.361) (70)

Other individuals accepted the confirmation of a diagnosis and took it as a sign to begin the process of planning for the future.

> "Receiving a diagnosis helped caregivers accept the new reality and move forward. Caregivers could begin to plan for care and adapt in cases where their family members were diagnosed with a dementia." (p.115) (36)
>
> "For another caregiver, a diagnosis prompted discussion and planning with his wife's family doctor about the possibility of long-term care placement in the future. This might not have otherwise occurred." (p.116) (36)
>
> "'So having the diagnosis sort of was like a confirmation and although tinged with, with sadness it was like a right this is what this now means, get on with it, you know' (Aged 33, caregiving for her husband, diagnosed with FTD)." (p.605) (71)

The most prevalent topic regarding the future was long term care placement and in particular, the associated costs.

> "Caregiver: It's not just the caring and nurturing and all that, it's like where's the money coming from if he has to go in somewhere." (p.4) (8)
>
> "Well he (family physician) does keep saying, put him in a nursing home. I can't afford it." (p.4) (8)

Healthcare providers can play a role in facilitating these conversations which may help ease the transition. One caregiver describes a scenario where this did not occur.

> "If someone had just said at the time, she can still live at home for a while, then I would been able to look into nursing homes in the meantime. Then I would definitely have looked around. What I now suddenly have to do at a moment's notice, I could have taken my time over." (p.274) (53)

The research literature appears to be predominantly focused on the diagnostic stages of the healthcare experience, in particular the experience of obtaining a diagnosis. However, as what happens after the diagnosis is increasingly explored, it is important to remember to consider the theme of the future and the role it plays in an individuals' experiences.

Theme: Positive experiences

Dimensions: timely care; knowledgeable and caring healthcare providers

The final descriptive theme is that of positive experiences. Each of the descriptive themes so far has largely highlighted gaps in the healthcare experiences with some exceptions presented. However, this theme focuses specifically on the positive healthcare experiences which stood out, as this may help to identify commonalities in positive experiences. Positive experiences included diagnostic experiences, which were timely and carried out by healthcare providers perceived to be knowledgeable.

> "The family doctor did wonderful… She did the MiniMental right away, uh and put him on the [Rivastigmine]… I couldn't have asked for anything better … she ordered several different kinds of tests. So she wanted to be sure that her diagnosis was correct." (p.377) (58)

> "The positive experiences related to timely intervention, advice and investigations leading to appropriate diagnosis and management." (p.643) (72)

Positive experiences were also facilitated by healthcare providers adapting to the situations of persons living with dementia and caregivers, and who were able to convey that they are knowledgeable, caring, and could be trusted.

> "Carers really appreciated bilingual/bicultural workers, GPs and other staff who worked with them to follow up referrals and ensure that families were matched up with services that suited their needs." (p.6) (73)

> "Open communication, helpful factual information and empathy went a long way toward family caregivers' positive feelings about their interactions with the doctor: "The doctor was very concerned and very helpful. He answered all my questions truthfully. In fact, I had a change of doctors due to retiring and my next one was just as helpful." (p.25) (74)

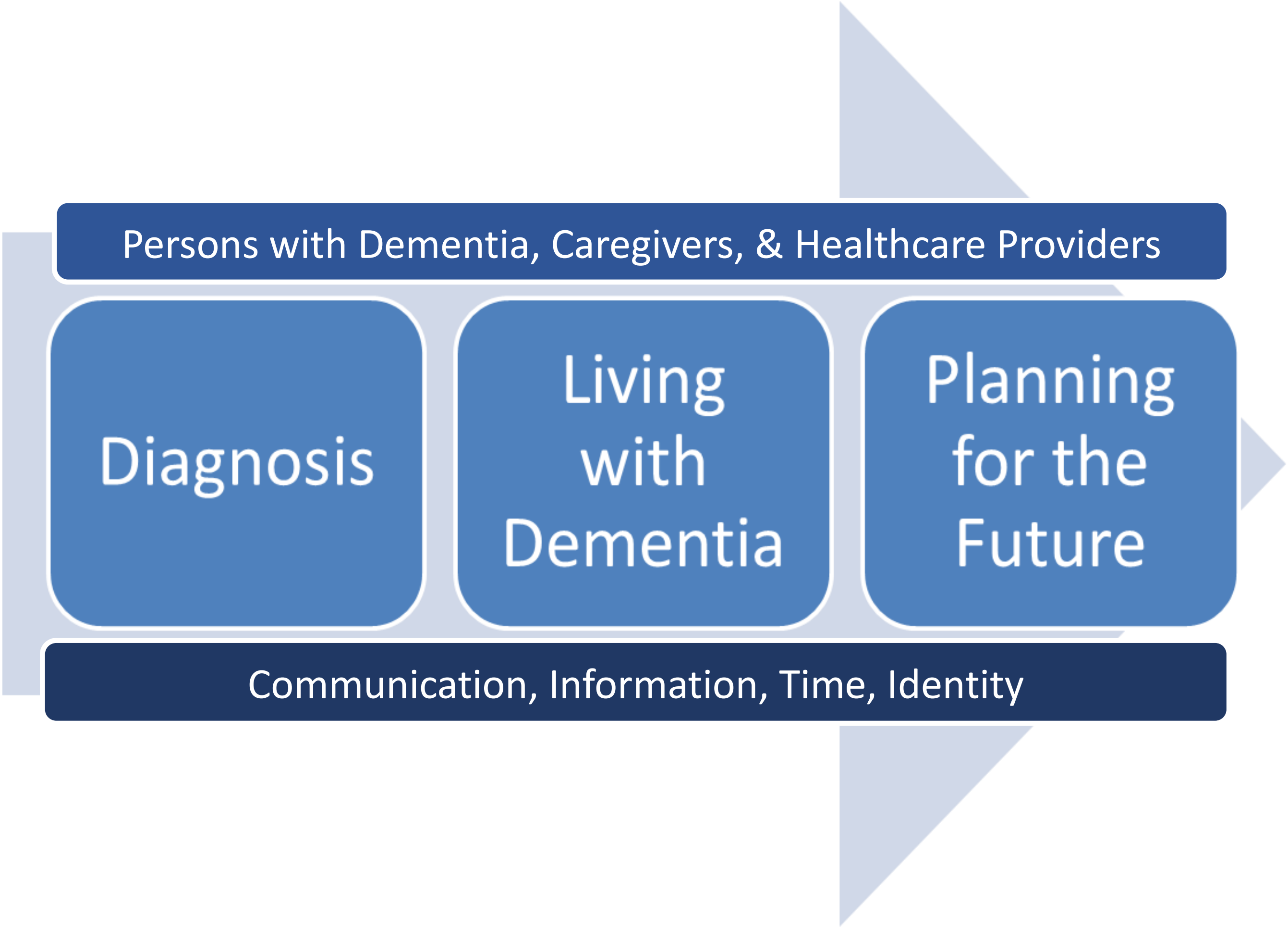
> "Finally, everyone who had been assessed and diagnosed in their own homes reported a positive experience, including feelings of support, familiarity, comfort and confidence." (p.64) (57)

Though this was the smallest of the descriptive themes identified in this synthesis, it still serves to highlight aspects of the healthcare experience that are important to persons living with dementia and their caregivers. Moreover, the positive experiences described by participants in the quotations presented in support of this theme encompass elements of positive experiences found in other descriptive themes such as communication, relationship with healthcare provider, information, diagnosis, time, and supports and services. The interpretation of these and the other descriptive themes into analytical themes presented as a model of healthcare experiences follows in the next section.

3.3.5. Thematic synthesis results: analytical themes

Following the identification of the eleven descriptive themes, the themes were reviewed, refined and organized into my own interpretations of the data resulting in the generation of analytical themes. This is in accordance with the methodology previously outlined for a thematic synthesis. The analytical themes were organized graphically into a model of the dementia healthcare experience for persons living with dementia and their caregivers. The main components of the models are the stages of the journey, the main individuals involved in the dementia healthcare experience, and what appear to be common threads throughout the stages for each of the individuals involved. The model is presented in Figure 7.

Figure 7: Model of the healthcare experiences of persons living with dementia and their caregivers



At the centre of the model are three stages of the healthcare experience which were identified: diagnosis, living with dementia, and planning for the future. The diagnosis stage encompasses the pathway to diagnosis as well as the diagnostic process itself, including experiences with diagnostic testing, delivery of diagnosis, and the emotions and reactions individuals may have to a diagnosis which have been previously described. Following diagnosis, persons living with dementia and caregivers must proceed to living with dementia. It is in this stage that provision of relevant information as well as access to necessary supports and services appear to play a particularly central role. The beginning of this stage is the point in which the role of an individual who can act as a system navigator might be most helpful. Such an individual would be able to direct the persons living with dementia and caregivers to the services which best support their needs. This individual could also play a role in helping individuals identify the questions they might need to be asking in this stage and/or helping them to find the information to answer questions they may already have. Once persons living with dementia and caregivers have settled into a ‘new normal’ in the living with dementia stage, as many individuals describe it, some individuals begin to proceed to planning for the future. Planning for the future includes giving thought and consideration to decisions regarding leaving home and palliative care. Not all individuals proceed to this phase, as some individuals may choose to delay decisions regarding future planning until absolutely necessary, such as in a crisis situation which necessitates an individual leaving his or her home into a long-term care facility.

Three groups of individuals played central roles in the healthcare experiences across the three stages: persons living with dementia, caregivers, and healthcare providers. In particular, it was the interactions between these three groups that shaped the healthcare experiences significantly. These interactions included the relationships of persons living with dementia and caregivers with the providers (whether there was trust, respect, dignity, empathy), as well as persons living with dementia and caregivers working together with providers. It was evident that persons living with dementia and caregivers had certain expectations of their providers and these expectations as well as their experiences varied depending on the type of healthcare provider (e.g., specialists seemed to be more highly regarded). Interactions between healthcare providers themselves were also an important part of the experience, as these interactions could either positively or negatively impact coordination of care.

The themes of communication, information, time, and identity were found to weave throughout each of the stages of the dementia healthcare experience. In particular, the themes of communication, information, and time could serve to either positively or negatively alter the dementia healthcare experience at each stage. For example, good clear communication between healthcare providers and persons with dementia and their caregivers was demonstrated to improve the experience of receiving a diagnosis. Similarly, the provision of information that was congruent with the needs of persons living with dementia and their caregivers in any of the given stages improved the healthcare experience. Time also played a significant role. Prolonged paths to diagnosis resulting in increased time to diagnosis, long wait times for referrals to specialists and supports and services, as well as the time persons living with dementia and caregivers were given in an encounter with a healthcare provider are all examples of aspects related to time which could alter the healthcare experience either positively or negatively. Finally, the theme of identity was also identified across the three proposed stages of the dementia healthcare experience. Preservation of identity was an important part of the healthcare experiences for both persons living with dementia and caregivers. Though it was apparent in the literature that roles evolve, persons living with dementia and caregivers still valued being treated with respect, dignity, and as individuals who have something to contribute in the healthcare encounter, rather than being discounted. Their identity as a person remained important regardless of the stage of the experience. In instances where the healthcare provider did not recognize the value to a person living with dementia or caregiver of maintaining and having one’s identity respected, the healthcare experience was found to be less positive.

The model of dementia healthcare experiences provides an overview of the dementia healthcare journey, including its key players and central themes throughout the stages of the experience. It also serves as the basis from which topics for the healthcare experience questionnaire were drawn. This process is detailed in the following chapter of this thesis. The section which immediately follows presents key points for consideration as well as strengths and limitations of this phase of the project.

3.4. Discussion

Phase I of this project developed a foundation for the phases which follow by providing a thorough overview of the topic area of the healthcare experiences of persons living with dementia and their caregivers, resulting in the development of a model of these experiences. This was achieved by means of a review of the qualitative literature, specifically employing the thematic synthesis methodology. As with any research methodology, there are several strengths and limitations to this approach.

A major strength is that following a thematic synthesis methodology allowed for a systematic approach to the collection, extraction, and analysis of the data. All steps were recorded should an individual wish to review how the synthesis was conducted. Though the synthesis could not be exactly reproduced, as development of the descriptive and analytical themes is dependent on my interpretation of the data, it would be possible for an individual to follow the thought processes. Moreover, coding was conducted using qualitative analysis software which would allow an individual to quickly identify which data supported any given theme. This facilitates the transparency of the reporting. Codes were also reviewed for consistency of coding. The thematic synthesis could have benefited from the review of codes and themes by another individual, which could help mitigate the susceptibility of the analysis to my own personal biases. My own experiences as outlined in section 1.3 may have affected my interpretation of which data belonged to a certain code and how those codes fit into the themes, which may not have necessarily been how another individual might code or collapse codes. If another individual had reviewed the data, there may have been some codes/themes we agreed on and others that we could have reached consensus through discussion, thus mitigating the effect of my inherent biases on the data. Similarly, though the final model received feedback from members of the thesis committee, it was not reviewed by persons living with dementia or caregivers who may have been able to provide valuable feedback. Further validation and refinement of the model could be explored in future work.

Thematic syntheses do not require the identification and inclusion of every available study on a given topic, but rather may be conducted until conceptual saturation occurs.(33) However, in spite of this, all available studies on this topic area were reviewed even beyond conceptual saturation to ensure a thorough review. In addition, following completion of the analysis of identified studies, I sought out further studies which could be negative cases. Additionally, I sought to identify studies in topic areas which appeared to be less represented in the literature. For example, there was very little research in the area of the palliative healthcare experiences of persons living with dementia and their caregivers. By analyzing all available studies and seeking to supplement areas which appeared to be underrepresented in the research literature, this thematic synthesis was thoroughly informed and supported.

A common criticism of thematic syntheses and of qualitative reviews in general is the risk of decontextualizing findings through their summarization and synthesis.(33) Typically, the results of qualitative studies are not meant to be generalizable and are specific to the context in which they were collected. However, the sheer volume of available qualitative research makes it difficult for an individual to review, rendering syntheses necessary. Table 3, located at the end of this chapter, provides details regarding study characteristics such as country, setting, types of participants, and study purpose which may help to provide some context to the studies which informed the synthesis. These details provide some indication of the contexts to which the results might be generalized. For example, no countries from Africa and very few from Asia were included in the review. Therefore, the findings from this synthesis cannot be applied to the healthcare experiences of individuals in countries from those continents. The analyses were conducted and the conclusions should be interpreted with the characteristics of included studies in mind.

An additional strength of this thematic synthesis is the inclusion of a quality assessment of the studies. The reporting of qualitative data was assessed using the COREQ criteria.(30) In quantitative reviews, sensitivity analyses may be conducted to assess the contribution of higher versus lower quality studies to the final results of the review. This is not as easily conducted in qualitative reviews. However, an approximate assessment of studies which were among the highest scoring on the COREQ criteria (23+ out of 32) versus those studies which scored in the single digits, shows more coded pieces of data in the higher scoring studies compared to the lower. The data which were coded were used to derive the descriptive themes. As more pieces of data were coded from higher quality studies, the descriptive themes would be informed more by these studies than studies which were lower quality. Though this is not a statistical assessment as one is not possible, it does provide some indication that studies with higher scores may have contributed more to the synthesis than lower scoring studies.

It is important to note that methodologies for reviewing qualitative research, including thematic synthesis, are continually under development and improvement as these approaches are relatively young in their existence. However, there have been guidelines developed in this area to guide the assessment of qualitative reviews. The ENTREQ statement provides guidelines for enhancing transparency in reporting the synthesis of qualitative research.(75) Descriptions of each criterion are found in Appendix 3. Table 2 lists the criteria and the section where each item is addressed. Each of these criteria were met by the thematic synthesis conducted in Phase I.

Table 2: ENTREQ criteria addressed by thematic synthesis conducted in Phase I

Item	**Section where item is addressed**
1. Aim	3.1
2. Synthesis methodology	3.2.3
3. Approach to searching	3.2.1
4. Inclusion criteria	3.2.2
5. Data sources	3.2.1; 3.2.2
6. Electronic search strategy	Appendix 1
7. Screening methods	3.2.2
8. Study characteristics	3.3.2; Table 6
9. Study selection results	Figure 2
10. Rationale for appraisal	3.2.3
11. Appraisal items	3.2.3
12. Appraisal process	3.2.3
13. Appraisal results	3.3.3

14. Data extraction	3.2.3
15. Software	3.2.3
16. Number of reviewers	3.2.3
17. Coding	3.2.3
18. Study comparison	3.2.3
19. Derivation of themes	3.2.3
20. Quotations	3.3.4
21. Synthesis output	3.3.5; Figure 7

With regard to trustworthiness, the principles of credibility, dependability, transferability, and confirmability are often applied in qualitative studies. These may also be applied to qualitative reviews and syntheses, though are defined slightly differently within the context of reviews.(76) Credibility within the context of a qualitative review "refers to the extent to which the synthesis findings represent the data and results reported in the primary qualitative studies."(76) The strategies which were used to enhance credibility were researcher reflexivity, thick descriptions of the data, and defining what constituted the data for the review (in this case, all reported results in primary studies were specified as the data). The second criterion of dependability "refers to the transparency and auditability of the research process and ensures that the decisions made by the researchers are transparent."(76) Tong et al. recommend four strategies for enhancing the dependability of a review, each of which were completed in this review.(76) The search strategy was made explicit and shared in Appendix 1. Inclusion and exclusion criteria were also clearly specified. The process and tools for appraisal of studies were provided. Qualitative data analysis software (NVivo 11) was used which allows readers to follow how data were coded and themes were derived. Tong et al. define the third criterion of transferability as “the potential relevance and applicability of the findings to other individuals, populations, contexts and healthcare settings.”(76) This was achieved in this review through detailed description of the characteristics of the primary studies, as presented in Table 3. Finally, the fourth criterion of confirmability aims “to demonstrate that the findings are derived from the data and not misconstrued or imagined by the researcher.”(76) Though quotations from primary studies were provided in support of the descriptive themes, the strength of this criterion could have been improved through the involvement of other researchers who could have independently reviewed the data to confirm the results. This limitation was previously discussed in greater detail in this section (3.4).

In summary, Phase I of this project provided a thorough review of the qualitative literature regarding the healthcare experiences of persons living with dementia and their caregivers in primary and secondary care. The use of a thematic synthesis methodology allowed for a systematic review of the qualitative literature. Though this approach has its limitations, every effort was made to address these and conduct a methodologically sound review. The model which resulted from Phase I serves as a basis for the development of a measure of the healthcare experiences of persons living with dementia and their caregivers in Phase II. It also provides a high-level summary of the main concepts which emerged from Phase I. The process of measure development from this model, as well as the initial assessment of the measure by persons living with dementia and their caregivers, is presented in the chapter which follows.

Table 3: Characteristics of included studies

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Beernaert et al. [2016](77)	Belgium	To explore whether other seriously ill people and people at even earlier phases would also benefit from early palliative care	Both	Interviews	Thematic content and narrative analysis	0	6	21
Newton et al.(59) [2016]	United Kingdom (England)	To explore the views and experiences of people with dementia, their family carers and general practitioners on their knowledge and experience of accessing information about, and use of, assistive technology in dementia care	Primary	Interviews	Thematic analysis	13	26	23

Author [Year]	**Country**	**Objective/Focus**	**Setting (Primary or Secondary)**	**Data Collection Method**	**Analytical Approach**	**Number of Participants**		**COREQ Score**
						PWD	**CG**	
Prorok et al.(8) [2016]	Canada	Healthcare experiences of persons with dementia and caregivers in primary care	Primary	Focus groups	Thematic analysis	8	21	32
Regan(67) [2016]	United Kingdom	To investigate the motivations and experiences accessing dementia care health and social care services for a Muslim, Pakistani male with dementia	Both	Case study (Interviews and observations)	Critical Realist; Grounded Theory	1	0	23
Stirling et al.(35) [2016]	Australia	Experiences in nursing-led memory clinic	Secondary	Interviews	Thematic analysis	11	2	20
Woolmore-Goodman et al.(78) [2016]	Canada	Caring for a person with amnestic mild cognitive impairment	Primary	Interviews	Hermeneutic phenomenological approach	0	5	20

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Beernaert et al.(79) [2015]	Belgium	Family physicians' role in palliative care	Primary	Interviews & focus groups	Thematic content analysis	6	0	32
Boots et al.(69) [2015]	Netherlands	Needs and wishes of early stage dementia caregivers	Not specified	Focus groups	Inductive content analysis	0	28	20
Gillespie, Harrison, & Mullan(65) [2015]	Australia	To explore the medication management experiences of Australian ethnic minority family caregivers of people living with dementia	Both	Interviews & focus groups	Thematic analysis	0	29	16
Roberts et al.(80) [2015]	USA	To explore how older adults from three prominent ethnoracial groups experience cognitive decline and aging	Not specified	Focus groups	Grounded theory	0	8	14
Toms et al.(52) [2015]	United Kingdom	Attitudes toward self-management	Both	Interviews	Thematic analysis	13	11	22

Author [Year]	**Country**	**Objective/Focus**	**Setting (Primary or Secondary)**	**Data Collection Method**	**Analytical Approach**	**Number of Participants**		**COREQ Score**
						PWD	**CG**	
		held by people with early stage dementia and their family caregivers						
Turner et al.(81) [2015]	USA	Participant-described lived experience as well as participant-derived solutions to challenges faced by dementia family caregivers	Primary	Focus groups	Thematic analysis	0	42	22
Alm, Hellzen, & Norbergh(82) [2014]	Sweden	To explore four couples experiences in long-term ongoing structured support groups	Not specified	Interviews	Content analysis	4	4	21
Bamford et al.(56) [2014]	United Kingdom (England)	Understanding the challenges to implementing case	Primary	Interviews	Normalization Process Theory	6	10	18

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		management for people with dementia in primary care in England						
Barca et al.(83) [2014]	Norway	To explore how adult children of a parent with young onset dementia have experienced the development of their parents' dementia and what needs they have for assistance	Both	Interviews	Grounded Theory	0	14	17
Dean et al.(47) [2014]	United Kingdom	To investigate the experiences of people with mild cognitive impairment and their "advocates," particularly within	Both	Interviews	Content analysis; Grounded Theory	23	20	17

Author [Year]	**Country**	**Objective/Focus**	**Setting (Primary or Secondary)**	**Data Collection Method**	**Analytical Approach**	**Number of Participants**		**COREQ Score**
						PWD	**CG**	
		healthcare services						
Dodd et al.(39) [2014]	United Kingdom	To contrast patient, family member and professional experience of primary and secondary (usual) care led memory services	Both	Interviews	Not specified	13	15	25
Innes, Szymczynska & Stark(55) [2014]	Scotland	To explore the reported difficulties and satisfactions with diagnostic processes and post-diagnostic support	Both	Interviews	Thematic content analysis	6	12	15
Karlsson et al.(46) [2014]	England, Estonia, Finland, France, Germany, The Netherlands,	To investigate persons with dementia and caregiver views of inter-sectoral information, communication	Both	Focus groups	Content analysis	25	112	19

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
	Spain and Sweden.	& collaboration throughout the trajectory of dementia care						
Lewis(84) [2014]	USA	To explore the experiences of caregivers actively seeking formal end-of-life care for a loved one with dementia	Primary	Interviews	Phenomenology	0	11	23
Mastwyk et al.(43) [2014]	Australia	To explore how information should be presented from when disclosing a diagnosis of dementia	Primary	Interviews	Frequency counting of qualitative data	32	32	15
Morgan et al.(36) [2014]	Canada	To explore for the first time the experiences of rural informal caregivers in the period leading up to a diagnostic	Secondary	Interviews	Constant comparative approach	0	46	23

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		assessment at a memory clinic, their hopes and expectations of the assessment, and their experiences in the six months following assessment and diagnosis						
Poland et al.(85) [2014]	United Kingdom	Carers' views gained from experiences of medication management in dementia	Both	Focus groups	Thematic and narrative analysis	0	9	22
Riaz & Jose(86) [2014]	India	Experience of caring for persons with dementia in rural India	Not specified	Interviews	Phenomenological	0	10	18
Samsi et al.(57) [2014]	United Kingdom	To explore the experience of the assessment and diagnostic	Secondary	Interviews	Constant comparative analysis	27	26	18

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		pathway for people with cognitive impairment and their family carers						
Sun, Mutlu & Coon(87) [2014]	USA	To explore service barriers perceived by family caregivers and by service professionals in a U.S. Southwest metropolitan area where there are no organized Chinese communities	Both	Focus groups	Content analysis; thematic coding	0	6	20
Williams, Morrison & Robinson(71) [2014]	United Kingdom	To explore how family caregivers make sense of caregiving and cope	Not specified	Interviews	Interpretive Phenomenological Analysis	0	8	15

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Bunn et al.(88) [2013]	United Kingdom	To test and contextualize the findings of a systematic review of qualitative studies looking at patient and carer experiences of diagnosis and treatment of dementia.	Not specified	Interviews & focus groups	Use of coding frameworks	3	12	24
Ducharme et al.(89) [2013]	Canada	To document the lived experience of spouse caregivers of young patients in order to inform the development of professional support tailored to their reality	Not specified	Interviews	Phenomenology	0	12	19
Flynn & Mulcahy(90) [2013]	Ireland	To explore the impact of caregiving on	Not specified	Interviews	Thematic analysis	0	7	20

Author [Year]	**Country**	**Objective/Focus**	**Setting (Primary or Secondary)**	**Data Collection Method**	**Analytical Approach**	**Number of Participants**		**COREQ Score**
						PWD	**CG**	
		caregivers of individuals with early onset dementia						
Garcia et al.(91) [2013]	Canada	To explore the experience of francophone persons with dementia and their caregivers during the peri-diagnostic period	Both	Interviews	Content analysis	7	7	21
Gorska et al.(62) [2013]	United Kingdom	To develop a deeper understanding of the lived experience of people with dementia regarding their service-related needs	Both	Interview	Thematic content analysis; Constant comparative method	12	19	20
Johnson et al.(92) [2013]	Australia	To investigate the views of older people	Primary	Interviews	Thematic analysis	7	0	20

<table>
<tr><th rowspan="2">Author [Year]</th><th rowspan="2">Country</th><th rowspan="2">Objective/Focus</th><th rowspan="2">Setting (Primary or Secondary)</th><th rowspan="2">Data Collection Method</th><th rowspan="2">Analytical Approach</th><th colspan="2">Number of Participants</th><th rowspan="2">COREQ Score</th></tr>
<tr><th>PWD</th><th>CG</th></tr>
<tr><td></td><td></td><td>with mild cognitive impairment about decision making on driving cessation</td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Landmark, Aasgaard, & Fagerstrom(93) [2013]</td><td>Norway</td><td>To explore and describe relatives' experiences of people with dementia living at home and to reveal the relatives' needs for support</td><td>Primary</td><td>Focus groups</td><td>Content analysis</td><td>0</td><td>10</td><td>17</td></tr>
<tr><td>Manthorpe et al.(44) [2013]</td><td>United Kingdom</td><td>To increase understanding of the experiences of people developing dementia and of their carers, to inform practice and decision making</td><td>Secondary</td><td>Interviews</td><td>Constant comparative analysis</td><td>27</td><td>26</td><td>22</td></tr>
</table>

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Toot et al.(94) [2013]	United Kingdom	To identify which factors may lead to crisis for people with dementia and their carers and identify interventions these individuals believe could help in crisis	Primary	Focus groups	Inductive thematic analysis	18	15	20
Beattie et al.(95) [2012]	United Kingdom	To explore the views of younger people about their dementia and dementia care services	Not specified	Interviews	Comparative textual analysis; Grounded theory	14	0	16
Chrisp et al.(96) [2012]	United Kingdom	To identify factors at different points in the journey that delay and facilitate first contact with a healthcare provider	Secondary	Interviews	Thematic analysis	0	20	13

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Forbes et al.(68) [2012]	Canada	To enable healthcare providers, care partners, and persons with dementia to use dementia care information more effectively by examining their information needs, how these change over time, and how they access, assess, and apply the knowledge	Primary	Interviews	Thematic analysis	5	13	19
Lilly et al.(48) [2012]	Canada	To investigate the health and wellness and support needs of family caregivers to persons with dementia in the Canadian policy environment	Not specified	Focus groups	Thematic analysis; constant comparative method	0	19	21

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
McCleary et al.(97) [2012]	Canada	To explore experiences of South Asian Canadians prior to dementia diagnosis	Both	Interviews	Content analysis	6	8	19
Shanley et al.(73) [2012]	Australia	To address a lack of literature on the use of formal services for dementia by people from culturally and linguistically diverse backgrounds by examining the experiences and perceptions of dementia caregiving within four communities	Primary	Focus groups	Content and thematic analysis	0	121	21
While et al.(63) [2012]	Australia	To explore the perspectives of the person with	Primary	Interviews	Grounded theory; constant comparative	8	9	17

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		dementia and their carers to see if there were any significant differences in their medication management experiences when compared to those of older adults without dementia and their carers			method; thematic analysis			
Wolfs et al.(98) [2012]	Netherlands	To gain caregivers' insights into the decision-making process in persons with dementia with regard to treatment and care	Not specified	Focus groups	Grounded theory	0	26	18
Innes, Abela, & Scerri(99) [2011]	Malta	The experiences of dementia family	Not specified	Interviews	Thematic analysis	0	17	15

Author [Year]	**Country**	**Objective/Focus**	**Setting (Primary or Secondary)**	**Data Collection Method**	**Analytical Approach**	**Number of Participants**		**COREQ Score**
						PWD	**CG**	
		caregivers in Malta						
Leung et al.(58) [2011]	Canada	To explore the perceptions and experiences of problem recognition and the process of obtaining a diagnosis among individuals with early-stage dementia and their primary carers	Both	Interviews	Thematic analysis; Phenomenology	6	7	18
Morgan(66) [2011]	United Kingdom	To explore individual's personal experience with Alzheimer's disease	Not specified	Observation	Not specified	1	0	N/A
Shanley et al.(51) [2011]	Australia	To explore the experiences and needs of family carers of people with end-stage dementia	Not specified	Interviews	Thematic analysis	0	15	14

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Smith et al.(61) [2011]	Australia	To determine ways to overcome factors affecting the successful delivery of services to Aboriginal people with dementia living in remote communities, and to their families and communities	Not specified	Interviews & focus groups	Thematic analysis	0	N/R	14
van Vliet et al.(100) [2011]	Netherlands	To investigate the barriers to diagnosis and to develop a typology of the diagnosis pathway for early onset dementia caregivers	Both	Interviews	Constant comparative analysis; Grounded theory	0	92	17

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Chan et al.(101) [2010]	China	To explore lived experience of persons with dementia in Hong Kong and explore their service needs	Not specified	Focus groups	Phenomenological	0	27	15
Chaston(38) [2010]	New Zealand	To describe dementia in the younger person highlighting their experiences and those of their families	Not specified	Not specified	Not specified	N/R	N/R	5
Livingston et al.(102) [2010]	United Kingdom	To identify common difficult decisions made by family carers on behalf of people with dementia, and facilitators of and barriers to such decisions	Both	Interviews & focus groups	Thematic content analysis	0	89	17

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
McGhee & Atkinson(103) [2010]	United Kingdom	To create a theoretical explanation of the development of the relationship between key workers and lay carers involved in the care of an individual with dementia	Not specified	Interviews	Grounded theory	0	18	16
McLaughlin & Jones(104) [2010]	United Kingdom	To determine the information and support needs of carers of adults who have Down's syndrome and dementia	Not specified	Interviews	Thematic analysis	0	4	11
Orr(105) [2010]	United Kingdom	To share the author's experiences working as an assistant psychologist in two British	Secondary	Observation	Anthropological	N/R	N/R	11

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		memory clinics for the detection and treatment of dementia and to illustrate the significance that cognitive testing had for them						
Benbow et al.(34) [2009]	United Kingdom	Carers sharing their experiences through narratives	Primary	Narrative	Thematic analysis	0	8	N/A
De Jong & Boersma(53) [2009]	The Netherlands	To address the needs and wishes of informal caregivers when providing skilled psychogeriatric day-care in the Netherlands	Not specified	Interviews	Thematic analysis	0	9	28
Doherty et al.(106) [2009]	United Kingdom	To explore patients’ and carers’ journeys through older people’s mental health services	Both	Interviews	Process mapping	0	2	N/A

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Kim(107) [2009]	USA	To understand dementia caregiving and post-caregiving experience from the Korean-American family caregiver perspective	Not specified	Interviews	Transcendental Phenomenological Analysis	0	8	23
Millard & Baune(72) [2009]	Australia	To compares patient experiences in dealing with dementia with the perceived role of health care providers in providing dementia care	Both	Interviews & focus groups	Grounded Theory	8	29	12
Neufeld & Kushner(45) [2009]	Canada	To identify male primary caregivers' perceptions of nonsupportive and supportive interactions in	Primary	Interviews & focus groups	Thematic Analysis; Ethnography	0	34	18

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		relationships with kin and friends as well as professionals						
Stone & Jones(108) [2009]	USA	To identify sources of uncertainty for adult children with a parent who has been diagnosed with possible Alzheimer's disease	Not specified	Interviews	Grounded theory	0	33	16
Willis et al.(109) [2009]	United Kingdom	To complete a qualitative investigation into the satisfaction with the service of those assessed and treated using a memory clinic service	Secondary	Interviews	Content analysis	16	15	22
Cahill et al.(110)	Ireland	The subjective experience of	Secondary	Interviews	Thematic analysis	28	28	17

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
[2008]		new patients and their primary caregivers attending a memory clinic						
Carpentier et al.(64) [2008]	Canada	To gain a better understanding of barriers to care early in the caregiving career, from the first signs of illness to diagnosis	Both	Interviews	Content analysis	0	52	14
Cascioli et al.(37) [2008]	United Kingdom	To investigate the needs of those caring for a person with dementia and their satisfaction with current services	Not specified	Interviews; Mixed methods	Thematic analysis	0	45	16
Forbes et al.(111) [2008]	Canada	To explore the experiences of family caregivers who	Both	Interviews & focus groups	Thematic Analysis	0	39	16

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		received Canadian home and community-based services that aim to assist them in caring for their family member with dementia						
Millard(112) [2008]	Australia	General practitioner management of dementia	Primary	Interviews	Ethnography	8	29	20
Page, Grant, & Maybury(40) [2008]	United Kingdom	The experiences of service users and family carers during the early stages of implementing nurse prescribing from a memory clinic	Secondary	Interviews	Grounded theory; Constant comparative method	7	6	16
Robinson et al.(24) [2008]	Australia	To reveal views about dementia diagnosis derived from a	Primary	Focus Groups	Content and thematic analysis	0	17	14

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		larger study of information needs of carers of people with dementia						
Gibson et al.(113) [2007]	United Kingdom	Comparative evaluation of a community-based and a clinic-based memory service	Secondary	Interviews	Template analysis	10	10	15
Downs et al.(70) [2006]	United Kingdom	To examine carers' accounts of contacts with general practitioners and general practice teams when they were first approached with concerns about their relative	Primary	Interviews	Not specified (“3 stage coding technique”)	0	122	12
Huizing et al.(114) [2006]	The Netherlands	To explore whether the ethical concerns raised in the	Secondary	Interviews	Not specified	0	12	13

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		literature are actually in line with experiences in the daily practice of dementia care, with regard to use of cholinesterase inhibitors						
Rimmer et al.(115) [2005]	France, Germany, Italy, Poland, Spain, United Kingdom	To explore public awareness and understanding of Alzheimer's Disease	Not specified	Interviews; Mixed methods	Not specified	96	0	7
Hinton, Franz, & Friend(42) [2004]	USA	(1) To describe pathways to diagnosis from the perspective of family caregivers and (2) to compare help-seeking patterns and experiences	Both	Interviews	Not specified	0	39	19

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		across three ethnic groups						
Shaji et al.(50) [2003]	India	To explore care arrangements for people with dementia and the strain experienced by their family caregivers	Not specified	Interviews	Not specified	0	17	18
Bruce et al.(10) [2002]	Australia	To investigate the circumstances that led general practitioners to refer persons with dementia and their carers to community support services	Primary	Interviews	Not specified	0	21	21
Holroyd, Turnbull, & Wolf(116) [2002]	USA	To examine the experience of patients and families when a diagnosis of	Not specified	Survey – with open-ended questions	Not specified	0	57	N/A

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		dementia is given						
Smith et al.(41) [2002]	USA	Exploration of caregiver needs	Both	Interviews	Ethnography	0	45	16
Butcher, Holkup, & Buckwalter(117) [2001]	USA	To describe the experience of caring for a family member with Alzheimer's disease or related disorder living at home	Not specified	Interviews	Phenomenology	0	103	19
Mason & Wilkinson(118) [2001]	Scotland	Reasons for stopping driving, how that decision was made, and views on driving assessments	Primary	Interviews	Not specified	36	0	8
Venohr et al.(49) [2001]	USA	To better understand the needs of caregivers, including their experiences with	Not specified	Focus groups; Mixed methods	Not specified	0	145	12

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
		the medical care system and community services						
Bruce & Paterson(11) [2000]	Australia	To understand how carers of persons with dementia gain access to community support and to determine potential barriers for carers	Primary	Interviews	Content analysis	0	24	23
Boise et al.(74) [1999]	USA	To examine factors which delayed obtaining a diagnosis for a dementing illness	Primary	Focus groups; Mixed methods	Not specified	0	53	14
Liken(119) [1999]	USA	To examine carers' experiences with interdisciplinary geriatric care teams	Both	Interviews	Grounded Theory; Constant comparative method	0	23	17

Author [Year]	Country	Objective/Focus	Setting (Primary or Secondary)	Data Collection Method	Analytical Approach	Number of Participants		COREQ Score
						PWD	CG	
Simpson(120) [1997]	United Kingdom	Carers as equal partners in care planning	Not specified	Questionnaire; Mixed methods	Grounded theory	0	20	15
Nolan & Keady(60) [1995]	United Kingdom	The experiences of dementia caregivers with Community Practitioners	Primary	Interviews; Mixed methods	Thematic content analysis; Constant comparative approach	0	38	14
Williams, Keady, & Nolan(54) [1995]	United Kingdom	Learning from caregiving experience of carer of person with early onset Alzheimer's Disease	Both	Case history written by carer	Not specified	0	1	N/A
Wilson(121) [1989]	USA	To explore the lived experience of family caregivers	Not specified	Interviews and Observations	Grounded theory; Constant comparative method	0	20	21

Chapter 4 Measure Development

Abstract

Objective: The aim of the second phase of this three-phase project was to consult with persons living with dementia and their caregivers to obtain feedback on a developed measure of the healthcare experience of receiving a diagnosis. The feedback was to be used to refine and finalize the measure.

Methods: Results of the thematic synthesis in Phase I were used to identify measure domains and individual measure items. Persons living with dementia and caregivers were recruited to participate in individual, dyad, or focus group interviews (participant choice). Topics of discussion included whether anything was missing, suggested changes, ease of completion, and positive aspects of the measure. Interviews were recorded and transcribed. Data were analyzed using inductive content analysis.

Results: In total, 13 persons living with dementia and 16 caregivers participated. Participants found the measure easy to read. The measure was limited to one page for conciseness, however participants expressed that a longer measure would be acceptable if it meant covering all topics they deemed pertinent. Discussion with the healthcare provider regarding driving was identified as a missing topic. Participants also expressed that the healthcare experience is complex with many individuals involved. Greater clarity was needed in the instructions regarding which aspect of the experience the measure is assessing.

Conclusions: Participants provided valuable feedback based on their lived experiences resulting in improvements to the measure. The revised measure was deemed suitable to undergo psychometric testing in the final phase of this project.

4.1. Introduction

Phase I of this project resulted in a model of the healthcare experiences of persons living with dementia and their caregivers in primary and secondary care. As was described previously, this person-informed model was developed from the published literature on this topic area. It was used to develop a measure of the healthcare experiences of person living with dementia and their caregivers as will be described in the section which follows. Phase II of this project also entailed going beyond the published literature to obtain feedback on the measure from persons living with dementia and caregivers who have themselves gone through these healthcare experiences.

Persons living with dementia and their caregiver have played pivotal roles in research pertaining to the exploration of their healthcare experiences. The ability of persons living with dementia to participate in research and to provide meaningful feedback on their experiences had previously been discounted.(122, 123) A 2012 review of all studies published in the Journal of the American Geriatrics Society in 2008-2009 (n=434) found that persons living with dementia are frequently excluded from studies, often without rationale.(124) Only a minority (43%) gave any reason for exclusion of persons living with dementia.(124) Sixteen percent of the articles examined used recruitment methods which were likely to minimize participation by persons living with dementia.(124) However, it is beneficial to involve persons living with dementia in research and to solicit their perspectives. As one person living with dementia who authored an article on the topic stated, “What a hugely missed opportunity it would be if people with Alzheimer’s were excluded from the very thing that could be used to gain a fuller understanding of their disease.”(125) Therefore, this project sought to solicit feedback from persons living with dementia and their caregivers on the developed measure. It was anticipated that these individuals could provide their opinions on the appropriatness and relevance of included items as well as on the design of the measure itself. The thoughts and suggestions shared by participants served to improve the measure before it underwent psychometric testing in the third and final phase of this project.

4.2. Methods

4.2.1. Identifying measure items

The analytical themes and model resulting from Phase I were used to identify tool domains and develop a draft measure. It was initially proposed that the measure would encompass all stages of the dementia journey. However, upon development of the model, it was evident that this would result in a measure too broad in scope. Moreover, individuals to whom the measure would be administered might not have yet experienced each stage of the journey. Consequently, there would be several sections of the measure which would not be applicable to these individuals. Therefore, it was decided to focus solely on the first stage, namely diagnosis, and design the measure to assess the diagnostic healthcare experiences of persons living with dementia and their caregivers. The diagnostic stage has been most deeply explored in the literature, would be applicable to all potential users, and is the first step chronologically in the dementia healthcare experience.

At the project proposal stage, it was also anticipated that two versions of the measure with distinct content would be developed; one for caregivers and for persons living with dementia. This was because two frameworks/models were anticipated. However, Phase I resulted in a single common model and one measure was developed based on domains from this model. Caregiver and person living with dementia versions of the measure were developed, however all questions were the same. The only difference was in the instructions, which on the person living with dementia version asked respondents to think back to their diagnostic experience versus the caregiver version which asked respondents to think back to his or her family member or friend's diagnostic experience. The person living with dementia and caregiver versions of the measure are found in Appendix 4 and Appendix 5 respectively. Table 4 presents the analytical themes, descriptive themes, and dimensions from the Phase I thematic synthesis which informed the questionnaire item development.

Table 4: Analytical themes, descriptive themes, and dimensions informing questionnaire item development

Questionnaire Item	Applicable analytical themes	Applicable descriptive themes and dimensions
1. The wait time for an available appointment was reasonable.	• Time	• Timeliness of diagnosis and care
2. The appointment was rushed.	• Time	• Amount of time available in visit
3. The physician communicated clearly with me.	• Communication	• Delivery and communication of diagnosis • Quality of communication
4. The physician explained test results to me.	• Communication	• Communication between healthcare providers, persons living with dementia, and caregivers
5. I was treated respectfully during the appointment.	• Identity	• Relationship with healthcare provider • Respect, dignity, and trust

6. I was able to ask any questions I may have had at the time.	• Time • Information • Identity	• Amount of time available in visit • Breadth of information needed • Working together
7. The physician provided me with a reasonable amount of information.	• Information	• Breadth of information needed
8. The physician provided me with information that was relevant to me.	• Information	• Information needs congruent to stage of disease
9. The physician offered information which could help me maintain my current lifestyle.	• Information • Identity	• Information needs congruent to stage of disease • Supports and services tailored to needs • Role and identity • Preservation of self-worth and identity
10. I knew how to obtain support if needed following this appointment.	• Information	• Information needs congruent to stage of disease • Supports and services • Making connections

The measure was developed keeping in mind conciseness, particularly given the target population for the measure. The measure was limited to one page (front and back). The items were developed in accordance with the analytical themes found to be present across the stages in the healthcare experiences framework: communication, time, information, and identity. Though no particular reading grade level was aimed for, an effort was made to avoid the use of jargon and terms which could interfere with comprehension.(126) I reviewed the items to ensure that there were no double-barreled questions, no value-laden words, and that items were of an appropriate length.(126) A bipolar Likert scale was used, allowing respondents to indicate the extent to which they agreed or disagreed with a statement. A larger font size was used and attention was paid to spacing of measure items and response options.

4.2.2. Participant recruitment

Persons living with dementia and their caregivers were recruited to participate in individual, dyad, or focus group interviews to provide feedback on the developed measure. As previously published literature has demonstrated, persons living with dementia of mild to moderate disease severity who have the capacity to provide consent are able to provide meaningful feedback regarding their experiences. Specific cut-points on a cognitive test such as the Mini-Mental State Examination or Montreal Cognitive Assessment were not used to determine ability to participate. Participants were included if they were able to read, write, and understand the study as explained both in the information letter and verbally.

Recruitment took place in the Okanagan region of British Columbia and in Southeastern Ontario between March 2017 and September 2017. Posters were displayed at seniors' centres and 25 long-term care and retirement residences in the Okanagan. The British Columbia Alzheimer Society also distributed copies of the posters to regional chapter offices in the Okanagan. In Southeastern Ontario, a connection was made with the Lived Experience Coordinator of the Alzheimer Society of Kingston, Frontenac, Lennox, and Addington. The Lived Experience Coordinator promoted the study to support group facilitators, who in turn shared posters, contact information, and information regarding the study with support group participants. Participants received a $30 Tim Horton's gift card as a token of their appreciation. Though it was evident that similar comments and feedback were continually being shared, an additional final focus group was conducted with four persons living with dementia and four caregivers, to ensure no new comments arose. Analyses conducted after the completion of data collection confirmed that this was the point at which saturation was reached.

4.2.3. Data collection and analysis

Data were collected through interviews and focus groups, depending on participant preferences. Interviews and focus groups have been previously used as methods to gather feedback on development of measures, such as a measure of level or quality of care provided by caregivers of individuals with Alzheimer's disease.(127) Persons living with dementia and caregivers were presented with an information letter and consent form to be completed prior to the commencement of the interview or focus group (Appendix 6). They were also asked to complete a demographic questionnaire (Appendices 7 and 8). Timing and locations of data collection were determined according to the preferences of participants. This is in accordance with the strategies for conducting research with persons living with dementia.(123, 128) The interview guide used to guide discussions is presented in Appendix 9. Topics of discussion included whether the participants felt that anything was missing, if they would change anything about the measure, their thoughts on ease of completion, and identification of positive aspects of the measure. Some participants also chose to fill out the measure and indicate their responses on paper as a means of allowing them to work through and think through the questions. These measures were collected from those individuals who chose to do so. All interviews were audio recorded and transcribed. Transcription was conducted by a hired third party. Memo notes were also taken during the interviews and focus groups. Immediately following each interview and focus group, I found a quiet spot alone to write my own additional notes and thoughts regarding the session. Proposed modifications to the measure which were identified as a result of the analysis were sent in a summary to participants for review. No responses were received.

Transcripts were analyzed using inductive content analysis. Content analysis has been described as a "research method for making replicable and valid inferences from data to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action."(129) Inductive content analysis moves from specific data to the development of more general categories.(129) It consists of three phases: preparation, organizing, and reporting.(129) The preparation phase includes selecting the unit of analysis and immersing oneself in the data through reading and rereading.(129) The unit of analysis selected was the interview or focus group. Each transcript was read through three times in order to immerse myself in the data. The organizing phase involves open coding and grouping of concepts.(129) Notes were written in text while reading. These were organized into sub-categories, ensuring all content was covered. The sub-categories were collected onto coding sheets and grouped into what are referred to as "generic categories."(129) These generic categories were then once again collapsed and formed the five main categories. Finally, the reporting phase can result in a conceptual model, map or categories.(129) The categories which were developed formed the recommended modifications to the measure and aspects of the measure to keep unchanged.

4.3. Results

4.3.1. Participant and study characteristics

Recruitment of participants in the Okanagan region proved to be challenging. Only two participants (both caregivers) took part in the study in this region, each in an individual interview. The interviews lasted 43 minutes and 24 minutes. Conversely, 27 participants took part in the study in Southeastern Ontario: 13 persons living with dementia and 14 caregivers. As previously mentioned, recruitment continued beyond the point of saturation. Based on published literature pertaining to sample sizes in qualitative research, it was anticipated that saturation would have been reached by approximately 30 participants (15 persons living with dementia and 15 caregivers).(130) This proved to be the case.

According to the preferences of participants in Southeastern Ontario, data were collected by means of one individual interview, two group interviews (one with two caregivers; one with a person living with dementia/caregiver dyad), and two focus group interviews each consisting of a mix of persons living with dementia and caregivers. The first focus group consisted of eight persons living with dementia and six caregivers. The second focus group consisted of four persons living with dementia and four caregivers. The interviews ranged from 25 to 54 minutes in length, with an average duration of 39 minutes. The focus groups were 80 minutes and 52 minutes in length. A caregiver from one of the group interviews also telephoned me to provide some brief follow-up thoughts after the session.

Demographic information regarding participants is presented in Table 5. The average age of persons living with dementia was 81.6 years old, while the average age of caregivers was 73.9. The majority of participants were female in both groups. Most of the caregivers were spouses and all but two of the persons living with dementia who participated lived with their spouses. In both groups, the majority of participants were married. Highest level of education completed and annual household income varied in both groups and is presented in greater detail in the table below.

Table 5: Participant characteristics

	Persons living with dementia (n=13)	**Caregivers (n=16)**
Mean age (range)	81.6 (72-90)	73.9 (51-87)

Gender (M:F)	5:8	6:10
Living Situation		
Alone	2	N/A
With spouse	11	
Relationship to person living with dementia		
Spouse	N/A	14
Child		2
Sibling		0
Friend		0
Other		0
Highest level of education completed		
Elementary school	1	0
High school	5	3
College	3	6
University degree	3	6
Postgraduate degree	1	1
Marital Status		
Single	1	0
Married or common law	10	16
Widowed	2	0
Divorced	0	0
Annual household income*		
$0 - $24 999	0	0

$25 000 - $49 999	4	5
$50 000 - $74 999	2	4
$75 000 - $99 999	2	2
$100 000+	1	4
Omitted response	4	1

* Several participants chose not to answer this question

4.3.2. Results of content analysis

As previously mentioned, transcripts and memo notes were analyzed using inductive content analysis. Individual interviews, two-person interviews, and focus groups were each coded separately. Memo notes were included within each type of interview/focus group for analysis. This method of analysis was chosen as there are different dynamics within each type of group which could affect the quality and quantity of data collected. Moreover, it allowed for any similarities and differences to emerge from the types of data collection approaches. The content analysis was conducted with the aim of identifying feedback on the measure. Upon analysis, it was found that five main categories emerged. All five were present in the group interview analysis, four of the five in the individual interview analysis, and a different four of the five in the focus group interview analysis. This will be further discussed as the categories are presented. The five main categories which emerged were: sharing of lived experiences, feedback pertaining to the content of the questionnaire, feedback related to process of completing the questionnaire, participants' interests in next steps of the study, and interview/focus group experience. The switch to the use of "questionnaire" in lieu of measure should be noted. Questionnaire was thought to be more of a familiar term, versus measure which was more formal and perhaps more abstract to participants. Questionnaire was used throughout the interviews and consequently the categories which emerged use this term.

Category: Sharing of live experiences

The sharing of lived experience category emerged in the individual and group interviews but was not present in the focus group interviews. Hypotheses for this difference are presented in the discussion section. In the individual and group interviews, participants were eager to share their dementia journeys. The first question in the interview guide was "What are your first thoughts about this questionnaire?" In many cases, the answer was not a reply to this question but rather the participants delving into their personal experiences. As I wrote in my memo notes, I initially found this to be frustrating as it was challenging to keep participants on the task at hand. The purpose of the interview was to gather feedback on the questionnaire, rather than to hear about their experiences. Consequently, this required a fair bit of redirection in the interviews. However, it did serve to build rapport with the participants. Moreover, in reflection I realized that what they were sharing of their experiences was valuable information. It provided insight into the aspects of their experiences which they found to be significant enough to share. In my memo notes, I wrote:

> "Then I also began to think that perhaps from his story, I could see which elements of the experience were important to him and use that to determine what should be important or included in the questionnaire. For example, his comment about the questionnaire being nicely laid out but the experiences in reality not being so. Or he talked a lot about the importance of care coordination. Of rapport with the healthcare provider. Those are all elements of the experience which I could try to incorporate into the questionnaire."

I also realized that perhaps the interviews could be modified to facilitate participants' desires to share their experience. I contemplated this in the following excerpt from my memo notes:

> “It is good to know their background and good to get their trust and build a relationship by hearing their story. Maybe it might be a good idea to ask them to tell me about their experience in obtaining a diagnosis. Then from there say, thinking back to that experience, if I were to hand you this questionnaire, what would be your thoughts on it in relation to that experience. This might help focus the interviews more and allow them to reference back as it seems that participants often are going back to talking about their experience and need redirection to answering about the questionnaire.”

Participants willingness and desire to share their experiences without being prompted may indicate that these individuals do not feel their stories are being heard, yet they need to be heard. The information shared by participants included details of their experiences, challenges they encountered, and their feelings regarding the healthcare system. The sharing of lived experience by these participants confirmed that they were well-equipped to provide feedback on what a questionnaire assessing the dementia healthcare experience should entail.

Category: Feedback pertaining to content of questionnaire

Sub-categories: Feedback on specific questionnaire items; missing topics

The next main category was the expression of feedback pertaining to the content of the questionnaire. This consisted of the sub-categories: feedback on specific questionnaire items; missing topics. Participants in the interviews and focus groups expressed concerns about questionnaire items nine and ten. Item nine was “The physician offered information which could help me maintain my current lifestyle.” This item was brought up in every interview and focus group for varying reasons. Some individuals felt that this was beyond the scope of a physician’s role.

> “Um, uh, well the physician really um doesn’t have much to do with anything outside of his office.”

> “I mean this is a family physician uh who treats you for these minor aches and pains and, hahaha, and to me this is something he doesn’t really need to get into.”

> "Mhmm…to help me maintain our current lifestyle…No, I , that all comes from the support group."

Others felt that the wording of the question was inappropriate, as they did not wish to maintain their current lifestyle due to a poor quality of life.

> "And, there, you know there's no, there's no lifestyle to preserve. There's ah the structuring of a new reality."

> "Help me maintain life! Hahaha Cause there's no lifestyle to maintain. It's centred around that person."

Others did feel that it was at least the role of the physician to facilitate a connection to resources which may be able to help with their lifestyle and quality of life.

> "I think that their job is to direct us here (Alzheimer Society)."

> "I was thinking about it as I filled it out, I said even if the doctors don't know all that stuff it would be nice if they had a little uh booklet, you know put together and anyone that went in, like if I went in with my Mum they would go you know "here's all the resources you're going to need" just so they don't have to spend the time going through it cause they are, they've got other patients to see but it would send us in the right direction."

Other participants agreed:

> "I agree with you one hundred percent…It would be nice to handed off so at least there's, that's not the end of it, it doesn't stop there. Here's some information for you to follow up on if you choose…"

> "Number nine is an interesting question; offering information that may help the person maintain current lifestyle…I think that is a very important question."

Overall, participants agreed that this questionnaire item was important to include. However, changes were made to its wording to take into account participants' expression of not having a lifestyle to maintain but rather wishing to improve their current situation. These specific modifications are discussed in section 4. 3. 3.

Question 10 stated "I knew how to obtain support if needed following this appointment." Participants expressed that they would like this questionnaire item to be more direct and imply that the physician took some action to direct the individual to available supports. Participants found this to be important.

> "I, personally I think they have to do something for ya, because I've heard many almost horror stories of a person being diagnosed and then just said "see ya", and they're out the door and they don't know what to do next. So it's kind of the uh doctor's office at that time giving you the tools to get the ball rolling."
>
> "Even if it's just an outline of what different places do, you can get services that are."

Modifications were made to the wording of question 10 to reflect the feedback received from participants.

As stated, the second sub-category was that of missing topics. The topic of driving was identified by participants as not covered by the questionnaire, yet they stressed that it should be. One participant pointed out that driving is a critical part of many people's lives and the revoking of a license comes up during that diagnostic appointment. Participants described their negative experiences with losing a driver's licence.

> "I didn't think there was anything wrong with my driving I didn't think I would lose my license. And suddenly somebody says "You know what, you can't drive home"
>
> "It would have been for us, it would have been very helpful had the uh doctor, who was the one who was giving this, approached the idea of not wanting to hurt someone, rather than (spitting kind of noise) your done."
>
> "Yeah, we had a similar experience and, and I complained about it actually after. The way it was done."

Based on the comments shared by participants, it was evident that the way driving cessation was approached could often be improved. This aspect of the healthcare experience warrants assessment and consequently a questionnaire item was added regarding driving.

Category: Feedback pertaining to process of completing the questionnaire

Sub-categories: Questionnaire design; administration of questionnaire; complexity of experiences

The process of completing the questionnaire was another main category which emerged. This category consisted of three sub-categories: feedback pertaining to the questionnaire design; feedback pertaining to the administration of the questionnaire; and the complexity of experiences which made the process of completing the questionnaire challenging. With regard to questionnaire design, participants shared feedback on the questionnaire length, layout/spacing, font size, and readability. Overall, these comments were positive. Participants shared:

> "Interviewer: Um, is there anything you like about this questionnaire when you read it over?
> P2: Well, it's pretty short. (laughter)"
>
> "Nice and clear and there is space if you wanted to add something."
>
> "They are very straightforward."
>
> "They are easy to understand."
>
> "I: Anyone else in terms of spacing or…
> P1: I have no problem.
> P12: It's a simple font. Nothing with a bunch of curls or…
> P11: Straightforward."
>
> "It's deadly clear to me."

Participants did however suggest some changes which they felt some could be made to the font and layout of the instructions to improve the clarity.

> "I thought your font size was good because um better for my eyes. But I also would have appreciated in your, in your little blurb at the top if you could have bolded the things that you wanted to focus on like diagnosis. I, I, It was the third time I read it before I realized this was a diagnosis that I needed."
>
> "Italics or something…underlined, um something that brings attention that you know, a family member diagnosis, um, circling appropriate answers, I don't know."
>
> "The key words, oh yeah….Underlining would be good in the important areas or a box around them or something, like something that makes it stand out."

This feedback was considered in making modifications to the questionnaire.

As participants went through the process of completing the questionnaire, several were interested in the details about how the questionnaire would be administered outside of this research study. More specifically, participants wanted to know details such as who would be administering the questionnaire, how would it be administered, and perhaps more importantly, when would it be administered.

> "Please uh, tell me uh, who's going to administer this?"
>
> "Mmm…so who's going to give this to who?"
>
> "We get a lot of papers these days and you're right it does need to be, be, there needs to be some accompanying..." (Participant drifted but was referring to need for person administering questionnaire to be prepared to explain the purpose and importance of it.)
>
> "Even you could have um, the pre-stamped envelope but like you said if they leave with it they might not do it. Could you fill it out here and put it in the envelope, seal it, and then I can mail it off." (Participant suggesting how the questionnaire might be filled out and returned.)

As stated above, participants brought up the important point of when to administer the questionnaire. They shared that it needs to be done with sensitivity and attention to how soon it has been since the diagnosis. Participants conveyed that there is a fine balance which must be struck between administering the questionnaire soon after the diagnosis so that details are not forgotten yet not too soon. Participants shared:

> "Well yeah, um one of the things is, when you ask this, it depends on when you ask this, give this questionnaire, because if it's right after your diagnosis has been made you're pretty well reeling and uh I was trying to think back, it was three years ago so, you know I can't even remember but I know that I was sort of like in a fog, in a daze. So it depends on where you are in the process, how you are going to answer this."
>
> "Certainly for me the sooner I would answer it the better cause I get kind of mixed up after all these appointments which one got from where but if you had asked P5

> that stuff right after, you would have, there was total denial, so you wouldn't have gotten any proper answers."

These are valid points brought up by the participants which would need to be considered when the questionnaire is used in practice.

Through the interviews, it was evident that the complexity of individuals' experiences made the process of completing the questionnaire challenging. As participants pointed out:

> "It's all nicely cut and laid out here. In reality, it doesn't happen that way."
>
> "It's as muddled as you can make it."
>
> "Diagnosis is a confusion of opinions…by a variety of people."

Participants made reference to the fact that there was often more than one physician involved in arriving at a diagnosis and that the process in and of itself could take years. This made it challenging for participants to decide what part of the diagnostic experience they should be focusing on in answering the questionnaire.

> "I think, you know people realize they've got a problem progressively. It's not like say, one day you say, 'Oh, I've got this arm that is aching."
>
> "We are talking about a process of five to seven years."
>
> "I'm confused maybe that's a better way of putting it. Because it really, it doesn't show my journey. It just shows little snippits. But in different areas like you know I could say I agree with this for Dr. A, I agree with this for Dr. B and altogether it worked because Dr. B didn't just say yes, he has that and we'll do these meds. He went further and got Dr. A involved. There was another step and then from there each time there was another connection."
>
> "My next question is who would you count on to be the largest player in this drama that we're talking about."

Though I had not asked participants to physically fill out the questionnaire in this phase, many still chose to do so as they found it helped them think through the questionnaire. I did not conduct analyses on the responses I received, however I did review the completed questionnaires as sometimes participants would jot comments next to questions. In one case, this helped me to identify an inconsistency between what a caregiver had expressed in an interview and how she had filled out the questionnaire. In my memo notes, I reflected on the individual's comments and her responses on the questionnaire:

> "She said no problem, finished it in less than 5 minutes. Said everything was clear etc. Interestingly though, she checked off multiple healthcare providers at the end. This shows that it's not actually clear in terms of getting people to think about that one specific experience. Perhaps if it were given to people immediately after the experience, that would be different. But as is, right now, it appears people are confused about what to think about. Or think about multiple providers at once."

On a different occasion, I reflected:

> "What experience are they supposed to answer this about? Was it with the family doctor? Was it with the psychiatrist? There's not just one and it appears hard for people to decide which one it actually is that they should be focusing on. I think the instructions will have to be modified. Maybe even with an example situation? And then definitely move up the question about the provider at the start so they know who they are answering about. I don't know if there would be benefit to a narrative question at the start?"

Adding to the challenges, in some cases participants did not know what kind of physician they had seen or in what setting:

> "If I may, what is a memory clinic? I'm sorry I've never, this is the first I've heard of it."
>
> "Do you know what the credential of Dr. A were? What is she?"
>
> "So what's, what's the difference then between the psychiatrist and the geriatrician?"

The complexity of participants' diagnostic experiences helped to identify challenges in the process of completing the questionnaire. Modifications were made to the questionnaire to address these challenges as best as possible.

Category: Participants' interests in next steps of the study

The next main category which emerged was participants' interest in the next steps of this study. It was evident that it was important to participants that the questionnaire be utilized after the research study. They shared:

> "Now are you going to be using this? It certainly is a lot of work."

> "I can appreciate what you are trying to get at. As I say, the important thing is its being put to use. You know uh, if it's just another survey, just another study, it's not going to do anything. It's a waste of my time. It's a waste of your time."

I also reflected in my memo notes:

> "Another common question – how will this be used?"

Two caregivers who participated in a group interview together made me think deeply about the purpose of the questionnaire and its utility. They found their experiences to be more complex than could be captured in the questionnaire and it made me question whether experiences could be captured in such a way:

> "These women have got me thinking long and hard about the purpose of this questionnaire, whether it can be done, and if one is developed, what will it tell you about the experience? What value will it add? As she said, her son would still have a different perception of the experience than she did. It's coloured/marked by the things you remember. The point of measuring experience vs satisfaction is that it's supposed to be more objective, but based on what they've said, will it actually be?"

Not only were participants interested in how the questionnaire would be used and its purpose, but they also wanted to know what would happen with the results of this questionnaire if it were administered in practice. One participant asked:

> "How, how would you follow up with um the categories that disagree? Like say I disagree with two or three items um…How would you, uh, what would be the follow up on that on your, on your side?"

Comments such as this demonstrate that participants truly wanted the questionnaire to be useful in bringing about change and improving experiences. One participant suggested that even just sharing the questionnaire with physicians in training could be one way to improve the experiences, as he/she felt that the questionnaire highlighted aspects of the healthcare experience which were important.

> "But this I would think would be invaluable for your, for your people who are training. Because they, because they do need to know because the population is top heavy with seniors and its getting top heavier with dementia…I think that they all need to be really uh education and understanding what's happening to all of us…These are things that they need to know that people react to and that people have needs in these areas and that they need to prepare themselves uh with you know…I really believe that."

Such comments made in the interviews, group interviews, and focus groups demonstrate that participants cared about this study producing useable results and cared about the improvement of dementia healthcare experiences. They took their roles as participants seriously and many provided thought-provoking comments. One participant even telephoned me a few days after our interview to share further thoughts as she had been continuing to think about the questionnaire. Overall, this was an engaged group of participants, interested in knowing where this study might lead to next.

Category: Interview/focus group experience

Sub-categories: dynamics; gratitude

The final main category which emerged was that of the interview and focus group experience. This category did not emerge in the individual interview transcripts, but was present in the group interview and focus group transcripts. This main category included two subcategories: dynamics; and gratitude. During the analysis, data emerged which spoke to the dynamics in the room. In my memo notes, on more than one occasion I noted a positive atmosphere in the room:

> "The group today was very positive."

> “Overall it was quite positive and I’m very happy with how it went.”

In the focus groups, this positive atmosphere may have been in part facilitated by the presence of their Alzheimer Society support group facilitator in the room. After one of the focus groups, I reflected:

> “X was great to have in the room as well. He knows the group well…They also obviously had a trusting relationship with him so I think it really facilitated their openness.”

Similarly, I felt that the presence of the caregiver in the group interview made the person living with dementia feel more comfortable in the interview setting. In my memo notes I noted:

> “I was concerned with the group interview that A (person living with dementia) might look toward B (caregiver) too much for answers or that he would dominate. I feel that both were able to share their responses to each question. I also feel that it helped A feel more comfortable having B there. I tried to make sure I asked her for her response if she hadn’t said something. Sometimes she would answer before him so I feel like there was a good balance between the two.”

I did however note individuals who were present in the room but did not actively participate. In my memo notes after one of the focus groups, I wrote:

> “There was one set of sisters who did not make any comments during the session except for a few comments in agreement. One of them even tried to give back her gift card because she felt she hadn’t participated as much or enough. Otherwise everyone who attended shared and participated.”

In the focus groups, I had placed recorders in two parts of the room to ensure I could pick up participants’ comments well from all areas. It wasn’t until I reviewed the transcripts from both recorders that I became aware of a participant (person living with dementia) who it turned out was not as willing to participate. The recorder picked up the following conversation between the person living with dementia and their caregiver:

> “P7: I didn’t write anything.
> P8: Do you want to say anything about your experience?
> P7: I don’t even want to talk to her.”

This is important to note as individuals such as this one may have had different experiences than those shared by more vocal participants. It is not possible to pinpoint the reason this person did not want to talk. It may have been due to a particularly negative experience, due to a lack of trust with me, or even something as simple as an off day. However, it is important to consider that there were individuals present with comments and experiences that were not shared.

Overall however, participants did express gratitude for the opportunity to take part in this study and for the work being done in this area of research. I noted:

> "Several people approached me after appreciative of the opportunity to take part."

One participant shared:

> "I'd just like to say thank you for all the work you are doing. All hard work and knowing that there's support. Thank you for your time."

Another even became emotional in her gratitude:

> "And I'm delighted that there's all this uh…I'm going to start crying."

The gratitude expressed by participants reflects the overall positive dynamics in the interviews, as well as the participants' personal values of truly caring to see improvements and advances in this area of research.

These main categories and the sub-categories within them, particularly the sub-categories related to the content of the questionnaire and the process of completing the questionnaire, were used to make modifications to the questionnaire prior to psychometric testing in Phase III. These modifications are presented in the section which follows.

4.3.3. Resulting modifications made to questionnaire

Several modifications were made as a result of the feedback from participants. The revised questionnaires can be found in Appendix 10 (persons living with dementia version) and Appendix 11 (caregiver version). The biggest modification was to the instructions of the questionnaire, with the aim of addressing the challenges participants had with deciding on which physician encounter to focus their responses. Question 11, which asked to which physician the respondent was referring, was moved to the start of the questionnaire so that the participants would have this person in mind as they circled their responses. Participants also suggested including the setting in which the diagnosis was made as well as an open space for comments and additional detail if needed regarding where and how the diagnosis was made. They stated that it was better to have this space and not use it than to need the space and not have it. Thus, an additional question regarding setting and an open-ended question with space for details were added. These questions along with the instructions were on a separate page, acting almost as a cover page. The remaining questionnaire items were on one page (front and back), stapled to the instruction page. At the suggestion of participants, a box was placed around the instructions and key words were bolded and underlined. It was hoped that these changes would help the participants focus their responses on one appointment by making participants think through the details of that diagnostic appointment before answering the remaining questionnaire items.

Questionnaire item nine appeared to give participants the most trouble. As was stated, participants' responses ranged from uncertainty whether this was within the scope of the physician's role to feeling that there was no lifestyle to maintain. It was decided to keep this question as many participants felt it should be included. The wording was modified to improving the respondent's current lifestyle rather than maintaining their current lifestyle.

Questionnaire item ten was also modified to better reflect the need for action by the physician with regard to providing information about available supports and services. The wording was changed from the participant "knowing how to obtain supports if needed following the appointment" to being "given information about available supports and services."

A new questionnaire item was added regarding driving as this topic was deemed missed yet important by participants. For many participants, their concerns with the experience of losing their or their family member/friend's license centered around the approach to revoking a license. The new questionnaire item asks whether the physician approached the topic of driving with sensitivity.

A couple of relatively minor modifications were also made to the questionnaire. Font size, spacing/layout, and wording were generally found to be appropriate throughout the questionnaire. However, the word "physician" was changed to "doctor" throughout at the suggestion of a participant. The word "over" was added on the bottom of the first page of the questionnaire to indicate that there is also a back side, as some participants didn't notice this until prompted. These minor changes along with the more major ones described above resulted in the revised version of the questionnaire which was tested in Phase III.

4.4. Discussion

Phase II built on Phase I by utilizing the developed healthcare experiences model to generate a measure of the healthcare experiences of persons living with dementia and their caregivers when receiving a diagnosis. Persons living with dementia and caregivers provided valuable feedback on the measure through individual, dyad, and focus group interviews. These qualitative data were analyzed through inductive content analysis. Analyses were conducted separately for individual interview data, group interview data, and focus group interview data. Based on the categories and sub-categories which emerged, modifications were made to the questionnaire resulting in a revised version to test in Phase III.

As reported in the results, there were some differences in the main categories which emerged in each of the approaches to data collection. Firstly, the category of sharing of lived experiences did not emerge in the focus group data. One hypothesis for this may be the fact that the focus groups consisted of participants who attended regular support groups with each other. Many of these individuals had attended support groups together for months and they were familiar with each other. Therefore, they already knew each other's stories and perhaps did not feel the need to share these once again. There were occasions where some aspects of individuals' personal experiences were shared, but it was not to the level of the individual and group interviews. There was very little redirection required in the focus groups to stay on the interview questions. Another hypothesis may be that participants did not feel as trusting of me as an interviewer and therefore did not wish to share their personal stories. However, I believe the former hypothesis is more plausible than the latter based on participants' body language and positive comments shared regarding the study.

The category of interview and focus group experience did not emerge in the data from the individual interviews. The sub-categories within this category were dynamics and gratitude. Perhaps it was simply the fact that it was just the interviewee and I and the dynamics between us were not as apparent as in the other sessions which had multiple participants. The individual interviewees also did not openly express their gratitude for participating to the extent that participants did in other sessions, though they were still positive and thankful. However, the data from the individual interviews did not support this emerging as a category.

Overall, there were many similarities between the individual interviews, group interviews, and focus groups as evidenced by the common categories and sub-categories in each. While categories such as sharing of lived experience and the interview and focus group experience may not have been common to all, the categories of the content of the questionnaire and the process of completing the questionnaire as well as their associated sub-categories were present across all qualitative data collected. This is important as these were mainly the categories which resulted in the modifications to the questionnaire. This is also important as this indicates that the changes made are reflective of comments made by participants across each of the three data collection methods. The other three categories served to provide more of a context of the data collection experience.

Phase II had several strengths and limitations. Firstly, recruitment of persons living with dementia to participate in research studies can be challenging. This study was able to recruit thirteen persons living with dementia to provide their input and feedback on the developments from Phase I. Unfortunately, I did not ask participants their diagnosis or how long ago they were diagnosed. This would have been valuable information, though I did not think of this until the analysis stage of Phase II. However, these questions were added to the data collection forms used in Phase III so that these details could at least be known about that participant group. The number of participants, both persons living with dementia and caregivers, was a strength as it increased the variety of individual's experiences, but also allowed me to see recurrent comments and reach a point of saturation.

Though a sufficient number of participants were recruited, the source of recruitment is a weakness. In all but one case, participants were recruited through the Alzheimer Society. This sample is likely not representative of the population. These are individuals who have managed to make a connection with the Alzheimer Society and obtain some support. There are many individuals who are not able or do not do so. These individuals may have had different experiences.

A second weakness is that in the focus groups in particular, it was a challenge to determine whether some comments were made by a person living with dementia or a caregiver.

Individuals sat in their dyads but I wasn't always certain which individual was the caregiver, unless they said something such as "When my husband/wife etc was diagnosed…" This made it difficult to assign comments to each type of participant in the transcript. In retrospect, I should have colour-coded the information letters which I gave to participants. That way I could tell who was speaking and that would better help me to assign comments in my notes and transcripts.

Trustworthiness in qualitative research is often assessed according to four components: credibility, transferability, dependability, and confirmability.(131) Strengths and limitations of this phase of the research can also be assessed within each of these components. Credibility can be assessed through strategies such as reflexivity, member checks, and peer debriefing or examination.(131) Throughout the process of data collection, I did reflect and note my thoughts, feelings, and interpretations of the experiences in my memo notes. Section 1.3 describes my reflexive standpoint. Analysis was conducted with this in mind. This strengthened the credibility of this qualitative work. As was previously stated, member checks were also completed. Credibility was not assessed through peer debriefing and examination. The analysis would have greatly benefited from this. In particular, I analyzed the individual interviews, group interviews, and focus group interview transcripts separately. Many of the categories and sub-categories which emerged were similar. This may be a product of the data. However, it may also be a product of some of my own inherent bias and the categories from one set of data being in my subconscious as I analyzed the next set of data. Peer debriefing may have helped to mitigate my bias and strengthen the analysis and credibility.

Transferability is the ability to transfer research findings from one group to another.(131) Several demographic data points were collected on participants, including age, gender, relationship between persons living with dementia and caregivers, living situation, education level, and income. This helped to provide a good description of the population. As was stated previously, two important data points which were not collected were diagnosis and time since diagnosis. This information would have been valuable to better describe the study population.

Dependability occurs when another researcher can follow the decision trail used by the researcher.(131) The use of qualitative analysis software helped with maintaining an audit trail. By looking at the analysis files, a researcher would be able to see exactly how the transcripts were coded and the data ascribed to each node. Moreover, coding trees were created which would allow a researcher to see how the data, codes, sub-categories, and main categories relate.

Finally, confirmability refers to the degree to which the results could be corroborated by another researcher.(131) Confirmability was achieved through memo notes, reflexivity, and use of qualitative analysis software which allowed for the development of an audit trail. In the case of the Phase II analysis, as presented above, the methods employed aimed to facilitate credibility, transferability, dependability, and confirmability. The data collection and analysis were conducted with these markers of rigour in mind, though as was described there were ways in which these could have been strengthened further.

It should also be noted that there have been challenges to these criteria for rigour in qualitative research. Morse et al. advocate for a process of verification to assess rigour in qualitative research.(132) Morse et al. propose that the Lincoln and Guba criteria for rigour are often employed ad hoc.(132) They argue that rigour must be actively built into the qualitative research process and that this can be done through the process of verification.(132) Morse et al. state: “Verification refers to the mechanisms used during the process of research to incrementally contribute to ensuring reliability and validity and, thus, the rigor of a study.”(132) Five verification strategies have been identified. While the work was undertaken with the components of rigour by Lincoln and Guba in mind, the qualitative work completed in Phase II also demonstrates several strengths and weaknesses in the context of verification.

The first verification strategy is methodological coherence, which aims to ensure congruency between the research questions and research methods employed.(132) The aim of Phase II was to solicit feedback from persons living with dementia and caregivers. While this could have been achieved through a survey about the questionnaire, I believe that the approach taken using interviews was the most effective way. It allowed me to ask clarifying questions when needed and similarly participants could clarify with me if they needed. Given the population, some individuals may have had trouble filling out a survey whereas all participants were able to express their thoughts vocally. Regarding analysis, inductive content analysis was an appropriate approach as it can be used to determine a “practical guide to action”. (129) This was my goal, with the action being the modifications to make to the questionnaire.

The second strategy is the appropriateness of sampling: “participants should be selected who best represent or have knowledge of the research topic.”(132) No one has better knowledge of the healthcare experiences of persons living with dementia and caregivers than these individuals themselves. As was previously stated, more could have been done to increase the variety of individuals included which would have increased the representativeness of the sample.

The third strategy is concurrent collection and analysis of data.(132) This was not done, mainly due to the timing of data collection. The majority of data collection occurred during my 8th month of pregnancy and the focus was on completing the data collection before my maternity leave began. Therefore, it was not possible to transcribe and analyze the data at the same time. Analysis was completed upon my return from maternity leave.

The remaining two strategies for verification are thinking theoretically and theory development. Thinking theoretically includes reconfirming ideas which have emerged from data in new data.(132) This was done to an extent, as thinking about the data, new ideas which were emerging, those which were repeated, was necessary in order to identify the point of saturation. However, if the concurrent collection and analysis of data had occurred, then this verification strategy would likely have been stronger. Finally, theory development is moving with deliberation between a micro perspective of the data to a macro conceptual/theoretical understanding.(132) This was not done as the aim of this phase of the study was not to generate any theories, but rather to identify the feedback provided by participants. Overall, Phase II was successful in the use of some verification strategies however the focus was on Lincoln and Guba’s criteria for ensuring qualitative rigour.

In summary, Phase II was effective in soliciting feedback on the developed questionnaire from persons living with dementia and caregivers. The results of the content analysis generated the modifications to be made to the questionnaire. A revised questionnaire was prepared for psychometric testing in Phase III. The process and results of the psychometric testing are presented in the chapter which follows.

Chapter 5 Psychometric Testing

Abstract

Objective: The final phase of this project aimed to test the psychometric properties of the modified measure with persons living with dementia and caregivers.

Methods: Persons living with dementia and caregivers were recruited to participate in validity and reliability testing. Face validity, content validity, construct validity, as well as internal consistency and test-retest reliability were determined. Face validity was assessed by asking participants to rate the suitability of the measure on a 5-point Likert scale. Content validity was determined through completion of a content validity matrix. Construct validity was determined by asking participants to rate the extent to which their expectations of their experience were met. This was correlated with total scores on the measure. Internal consistency was calculated using Cronbach's α. Finally, test-retest reliability was determined by asking participants to complete the measure on two occasions, two weeks apart. Due to difficulties in recruitment of persons living with dementia, most psychometric analyses could only be conducted with caregiver data.

Results: Three persons living with dementia and 18 caregivers participated. The measure demonstrated good content validity. Face validity was also found to be appropriate in both participant groups. Data from the caregiver group demonstrated good convergent construct validity, with a Spearman correlation coefficient of 0.71. Internal consistency was also found to be high (Cronbach's α = 0.78). Test-retest reliability was fair with an ICC(2,1) of 0.62.

Conclusions: The measure demonstrated good validity and internal consistency. Test-retest reliability was fair, though typical of similar measures. Further work is needed with persons living with dementia with regard to psychometric testing of the measure in this population.

5.1. Introduction

Phase III was the final phase of this three-part study. The first phase resulted in a healthcare experiences model which was used to develop a draft measure of experience. This measure was modified based on input from persons living with dementia and caregivers in Phase II. The final phase consisted of assessing the reliability and validity of the measure to determine the measure's psychometric properties.

In spite of the amount of research into various aspects of the healthcare experience of persons living with dementia and caregivers, there appear to be no tested and validated measures of experience for persons living with dementia and their caregivers. A quick search of the literature indicates the types of measures which do exist. Caregiver-related measures include measures of burden(133) and measures of competency in managing caregiver burden.(134) Symptom-related measures, such as the Patient-Reported Outcomes in Cognitive Impairment (PROCOG) also exist.(135) The PROCOG is a 55-item patient-reported measure for individuals with mild to moderate cognitive impairment.(135) It measures symptoms of cognitive impairment and their impact from the perspectives of persons living with dementia.(135) Measures have also been developed to measure depressive symptoms in persons living with dementia(136) as well as behavioural symptoms of persons living with dementia.(137) Though not measures of healthcare experience, there has also been considerable focus on dementia-related quality of life measures, both for persons living with dementia and caregivers.(138-140)

The Lewy Body Dementia Association attempted to measure the caregiver experience while seeking a diagnosis.(141) They developed an internet based survey which explored the caregiver perceptions of the difficulty obtaining a diagnosis for the patient and their experiences with their healthcare providers.(141) While a copy of this survey is no longer available, based on the published results of the study, it appeared to measure the number of physicians consulted, time from first visit to diagnosis, total number of office visits prior to diagnosis, specialty of the diagnosing physician, and first diagnosis given after initial symptom presentation.(141) Very little information is provided regarding survey design and its properties.

A measure of healthcare experience for persons living with dementia and caregivers is clearly an existing gap in this realm of research. The measure developed in this study covers a wider range of aspects of the diagnostic experience than measures such as the Lewy Body Survey. Moreover, its development and design have been thoroughly documented in Phase I and Phase II of this work. Phase III reports on the psychometric properties of the measure. Validity, including face validity, content validity, and construct validity, as well as reliability, including internal consistency and test-retest reliability, were determined in this final phase of the research study. Details regarding the psychometric testing are presented in the sections which follow.

5.2. Methods

5.2.1. Recruitment

Persons living with dementia and their caregivers were recruited to take part in the psychometric testing of the revised questionnaire. As in Phase II, specific cut-points on a cognitive test such as the Mini-Mental State Examination or Montreal Cognitive Assessment were not used to determine ability to participate. Participants were included if they were able to read, write, and understand the study as explained both in the information letter and verbally. Participants also demonstrated some recollection of their experience of receiving a diagnosis. Recruitment took place in Southeastern Ontario. The connections made in Phase II with support group facilitators from the Alzheimer Society of Kingston, Frontenac, Lennox, and Addington were utilized for recruitment in Phase III. These individuals shared posters, contact information, and information regarding the study with support group participants. An additional method of recruitment came in the form of a presentation of Phase II results at a local research day for various healthcare providers and service providers in the region for seniors. Following my presentation, two Alzheimer Society support group facilitators approached me with their business cards indicating that they knew of individuals who would be interested in participating. Finally, an advertisement was placed in the Saturday edition of a Kingston newspaper. Several responses were received because of this ad. These participants also recruited individuals that they knew who would be interested in participating. Participants received a $30 Tim Horton's gift card as a token of appreciation.

In the proposed methods for Phase III, it was indicated that individuals who had participated in Phase II would be excluded from Phase III. However, as was previously mentioned, I was on maternity leave between Phase II and Phase III. Therefore, there was an approximately eight month gap between when Phase II data collection was completed and Phase III began. This was considered to be a sufficient amount of time that individuals would not recall many specifics about the questionnaire. Therefore, individuals who had participated in Phase II were given an opportunity to participate in Phase III though only two individuals did (one person living with dementia and one caregiver).

5.2.2. Validity testing

Face validity, content validity, and construct validity were assessed. Face validity was determined through an approach outlined by Streiner and Norman. Streiner and Norman indicate that asking participants to rank the questionnaire on a 5-point scale from extremely suitable to irrelevant is sufficient for determining face validity.(126) Content validity was assessed using a content validity matrix.(126) Finally, construct validity was determined by asking participants a single global question about whether their expectations of the healthcare experience were met. Fulfillment of patient's expectations has been reported in the literature as a strong predictor of patient experiences.(14, 142) Therefore, it was anticipated that individuals who had expectations which were not met would endorse response options which indicated a more negative experience (convergent validation). A correlation coefficient was calculated to determine the correlation between expectations and experience. An a priori hypothesis of a correlation of 0.6 was selected. Scores from the first administration of the questionnaire were used for construct validation analyses. All statistical analyses were conducted using SPSS Statistics 24.

5.2.3. Reliability testing

Internal consistency and test-retest reliability were assessed. Internal consistency was calculated using Cronbach's α. In the proposal stage, this was not expected to be high as the questionnaire was predicted to cover the entire healthcare experience from diagnosis through to advanced management. However, based on the results of Phase I, the questionnaire was designed with a focus on the diagnostic stage. Therefore, good internal consistency was expected.

To assess test-retest reliability, participants were asked to complete the questionnaire on two occasions two weeks apart. This was thought to be a sufficient time period to ensure that participants did not remember their responses but not so long that any considerable deterioration in cognition would be expected. An intraclass correlation coefficient (ICC) was used to calculate the test-retest reliability. The required sample size was calculated using Kraemer and Thiemann's formula $\Delta = (\rho_1 - \rho_0) / (1 - \rho_1\rho_0)$, where ρ_1 is the desired reliability correlation and ρ_0 is an alternative comparison correlation.(143) The resulting Δ value was looked up in a Master Table which gave a value of *v*.(143) Given that an ICC was used, the required sample size was equal to $v + 1$.(143) A desired reliability correlation of 0.80 was selected, with an alternative comparison correlation (considered unacceptable) of 0.40. At a 0.05 significance level with 80% power and using a one-tailed test, this resulted in a Δ value of 0.588 and a v of 17. Consequently, the required sample size was 18 (17+1). A dropout rate of 10% was anticipated. Therefore, the aim was to recruit 20 persons living with dementia and 20 caregivers.

5.3. Results

5.3.1. Participant characteristics

As was previously stated, participants were recruited in South Eastern Ontario and more particularly in the Kingston, Frontenac, Lennox, and Addington region. Participants completed the questionnaires at a location of their choosing (e.g., Alzheimer Society office, coffee shops, libraries). Recruitment of persons living with dementia proved to be very challenging and the required sample size was not reached within the time frame of this thesis work. Only three participants were recruited to form this group. As the sample size of this group is quite underpowered, it is not possible to conduct statistical analyses such as test-retest reliability with this data. However, some data from this group, such as their responses to face validity, will be shared. These three individuals were spouses of caregiver participants. In each case it was the person living with dementia who had initiated the participation. The average age was 76 years and this group consisted of one male and two females. Two of the participants had Alzheimer's disease and one had vascular dementia. Mean time since diagnosis was 2.67 years.

The caregiver group consisted of four males and 14 females. Mean age was 70.3 years old. All but six were spouses; the remaining were children. Interestingly, all the caregiver participants who were children had been recruited through the newspaper advertisement or by other 'child' participants who had seen the newspaper advertisement. All the spouse participants were recruited through the Alzheimer Society. All of the caregivers were married. Education level and income varied. Diagnoses also varied and included Alzheimer's disease, vascular dementia, frontotemporal, and other. Mean time since diagnosis was 4.7 years, though the range was from 0 years to 18 years. Further details regarding both participant groups are found in Table 6.

Table 6: Participant characteristics

	Persons living with dementia (n=3)	**Caregivers (n=18)**
Mean age (range)	76.0 (67-85)	70.3 (52-85)
Gender (M:F)	1:2	4:14
Living Situation		
With spouse	3	N/A
Relationship to person living with dementia		
Spouse	N/A	12
Child		6
Sibling		0
Friend		0
Other		0
Highest level of education completed		
Elementary school	0	0
High school	1	6
College	2	6

University degree	0	4
Postgraduate degree	0	2
Marital Status		
Single	0	0
Married or common law	3	18
Widowed	0	0
Divorced	0	0
Annual household income		
$0 - $24 999	0	0
$25 000 - $49 999	1	5
$50 000 - $74 999	1	3
$75 000 - $99 999	0	1
$100 000+	0	5
Omitted response	1	4
Diagnosis		
Alzheimer's disease	2	8
Lewy body dementia	0	0
Vascular dementia	1	4
Frontotemporal dementia	0	1
Other	0	5
Mean time since diagnosis in years (range)	2.67 (2-3)	4.72 (0-18)

5.3.2. Validity testing

Face validity was determined by asking participants a single question regarding the suitability of the questionnaire. Five response options were given: extremely unsuitable [1]; somewhat unsuitable [2]; neutral [3]; somewhat suitable [4]; extremely suitable [5]. Table 7 shows the mean, range, and the distribution of responses regarding this question in each group. None of the "unsuitable" response options were endorsed. Mean score in the person living with dementia group was 3.7. The caregiver group mean was 3.9. This indicates that participants found the questionnaire to be suitable with regard to measuring the healthcare experience of receiving a diagnosis.

Table 7: Participant responses to face validity question

	Persons living with dementia (n=3)	**Caregivers (n=18)**
Mean (range)	3.7 (3-5)	3.9 (3-5)
Extremely unsuitable	0	0
Somewhat unsuitable	0	0
Neutral	2	3
Somewhat suitable	0	13
Extremely suitable	1	2

Content validity was determined through a content validity matrix. As the aim of the questionnaire design was to assess the experience within the context of the healthcare experiences model developed in Phase I, the elements of the model which were common across the dementia healthcare experience were selected as columns in the matrix. The matrix is found in the table below.

Table 8: Content validity matrix

Questionnaire Item	Communication	Information	Time	Identity
Question 1			X	
Question 2			X	
Question 3	X			
Question 4	X			
Question 5				X
Question 6		X	X	X
Question 7		X		
Question 8		X		
Question 9		X		X
Question 10		X		
Question 11	X			X

Completion of a content validity matrix helps to ensure that the questionnaire has a sufficient number of items to address all domains of the questionnaire. Each item should address at least one domain and each domain should be addressed by at least one item. In this case, two domains are addressed by three items, one by four items, and one by five items. The questionnaire items themselves include a mix of questions which address a single domain as well as questions which address multiple domains. As all domains and questionnaire items are addressed, the completed content validity matrix demonstrates that each questionnaire item serves a purpose and that all domains are covered.

In order to assess construct validity, participants were asked to indicate their level of agreement to the statement: "My expectations of my healthcare experience were met." Participants indicated their responses on a 5-point Likert scale (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree). The response to this was compared against the total scores on the questionnaire by calculating a Spearman correlation coefficient using the data provided by caregivers. Higher total scores on the questionnaire indicated more positive experiences. Higher scores on the global question indicated that experiences were met. The calculated Spearman correlation coefficient was 0.71, which indicates a good correlation between the two variables and was higher than the hypothesized correlation of 0.6. This correlation was found to be statistically significant ($p = 0.001$). Therefore, the questionnaire demonstrated good convergent construct validity.

5.3.3. Reliability testing

Reliability testing was conducted using only data from the caregiver group, given the small sample size of persons living with dementia. Internal consistency was calculated using Cronbach's α and was found to be 0.78 which can be considered good. There has been some debate regarding what is considered a good level for Cronbach's α, however it is generally accepted that 0.70 is considered good.(126) It should be noted that a Cronbach's α that is very high can indicate redundancy.(126) Streiner and Norman say that Cronbach's α should not exceed 0.90.(126) The calculated Cronbach's α in the case of this questionnaire falls within this acceptable range. Moreover, the Cronbach's α if item deleted fall between a range of 0.73-0.85, with only three of eleven items demonstrating a higher Cronbach's α than that of the overall value. This indicates that most of the items are important to the internal consistency of the measure.

With regard to test-retest reliability, mean time between administrations was 15.8 days (range: 13-27 days), which is close to the selected time frame of 14 days. An ICC(2,1) was calculated and found to be 0.62 which is fair though less than ideal. Nunnally recommends a minimum of 0.70 when a scale is to be used for research purposes.(144) Though test-retest reliability was not calculated using data provided by persons living with dementia, it is worth noting that the responses of these individuals mirrored that of their caregiver dyad participants. While the results from a small sample such as this cannot be generalized, it is encouraging in pursuing future testing with this population.

5.4. Discussion

Psychometric testing of the measure was completed in Phase III. The measure was found to have content validity as well as good face validity based on data from both caregivers and persons living with dementia, though the latter data were limited. Data from caregivers demonstrated good convergent construct validity. With regard to reliability, internal consistency was found to be high though test-retest reliability was fair.

There were several strengths and limitations in this phase of the research study. Firstly, the required sample size was reached for caregivers allowing the analyses to be sufficiently powered. No participants were lost to follow-up; all those initially enrolled were able to complete the study. Moreover, the proposed time frame between administrations of the questionnaire of 14 days was well adhered to, with 13/18 participants completing the retest within 14 days +/- 1 day. Though the data from persons living with dementia were very limited, the data collected are promising and offer support for pursuing further data collection with this population. Nevertheless, the inability to recruit the required sample size of persons living with dementia was a significant limitation and resulted in analyses largely based on caregiver data only.

The challenge in recruiting persons living with dementia is a reality of conducting research with this population. Several caregiver participants commented on the absence of the perspective of the person living with dementia. I journaled these comments following data collection sessions. One caregiver shared, “It really should be my wife filling this out, but she just isn’t able.” Another stated, “My mother would be willing to do this, but she just can’t.” The input of these individuals is missing though given the nature of the disease, it wasn’t possible to obtain it. As was stated previously, three persons living with dementia participated in the study. The caregivers of each of these individuals also participated in the study. This is not surprising as one would in most cases expect that a person living with dementia would participate with the caregiver at least present if not also participating. Participating in a research study involves making a decision to do so and it has been demonstrated in the literature that decision-making is often a shared process between the person living with dementia and caregiver dyad, with shared decision-making existing on a continuum.(145) The literature on involving persons living with dementia in research has identified the caregiver as one of the “gatekeepers” to involving persons living with dementia in research.(146, 147) Given that many caregiver participants expressed that their spouses or parents would not be able to participate and that persons living with dementia would likely participate with the caregiver present, this may explain the low number of participants in the person living with dementia group. This is reflective of the reality that when trying to understand the experience of a person living with dementia, it will often come with the involvement and/or participation of the caregiver.

A second limitation is representativeness of the participant group and generalizability of the results. It should be noted that the results of the psychometric analyses are only applicable to populations similar to that in which it was tested.(126) As was presented in section 4.3.1, there was no representation of individuals who had gone through the experience of a diagnosis of Lewy Body dementia. Moreover, all the caregivers were spouses or children of persons living with dementia; no other types of caregiver relationships had participated. All participants were married. The sources from which individuals were recruited also affect the composition of the participant group. As was stated, a large source of recruitment was the Alzheimer Society. Individuals who have managed to make a connection to this service may have different experiences than those who have not and may differ demographically from those who have not. The second primary source of participants was an advertisement in a local newspaper. A large portion of the distribution of this newspaper is by subscription which would once again likely reach only a certain portion of the population. The individuals who participated were openly very motivated to see dementia healthcare experiences improved, with several even stating that they didn't care about receiving a gift card for participation but just wished to see improvements in experiences. This once again speaks to the types of individuals who participated. The results should be interpreted with the characteristics of the participant population in mind.

Finally, while most of the validity and reliability testing demonstrated good results, the test-retest reliability was less than desirable. There are a few factors which could have played a role in this. Firstly, the mean time since diagnosis was 4.7 years with a range of 0 to 18 years. In some cases, participants were being asked to recall experiences several years, if not more than a decade ago. This can affect the clarity and accuracy of individual's recollections. In practice, the measure would be administered much closer to the experience in question. Secondly, when looking at the discrepancies between responses on individual questionnaire items, one can see that most of these are quite small. If participants did not choose the same response option for a questionnaire item on the test and retest, their responses were typically no more than 1-2 points apart. For example, a participant may have chosen agree on the first administration of the measure and strongly agree on the second administration. Participants did not typically change their opinions from agreeing to disagreeing or vice versa. However, cumulatively these small discrepancies may have resulted in a larger difference between total scores. This would have then negatively affected the overall reliability of the measure.

There are also several factors related to the design of the measure itself which may have affected its test-retest reliability. Firstly, the measure was designed to be concise and to keep the number of items to a minimum. Reliability tends to increase with increased test length.(126) Therefore, keeping the measure length short may have negatively affected the reliability. The test-retest reliability was also calculated in a relatively homogeneous population. When applied in a more heterogenous population such as that of the general population of dementia caregivers, one would expect the reliability to be higher.(126) Finally, a shorter test-retest interval may have improved the reliability(126) though given the time period since the experiences in question, this is unlikely to have had a significant effect.

It should also be noted that the acceptability of a calculated test-retest reliability can vary. Values deemed acceptable can vary based on whether the measure is to be used for clinical purposes or research purposes, with acceptability cut-offs of the former being higher than the latter.(126) A test-retest reliability of 0.62, while not ideal, is also not unacceptable for measures that have been developed and used in the realm of research with persons living with dementia and their caregivers. For example, a dementia quality of life measure known as the DEMQOL (for persons living with dementia) and the DEMQOL-Proxy (for caregivers), has demonstrated a similar test-retest reliability.(139) The 28-item DEMQOL underwent test-retest reliability testing with 10 persons living with dementia and a reliability coefficient of 0.76 was determined.(139) The 31-item DEMQOL-Proxy underwent test-retest reliability with 13 caregivers and a reliability coefficient of 0.67 was determined.(139) This is minimally larger than the reliability coefficient calculated in this study. The DEMQOL and DEMQOL-Proxy have gone on to be used in dozens of research studies with thousands of participants and have been translated to Chinese, German, Russian, and Spanish.(148) Therefore, while a higher test-retest reliability of the developed measure would certainly be preferable, it is not so low as to be prohibitive in its use in studies in this area of research in the future. Moreover, a review of psychometric testing of measures of patient satisfaction/experience in general found that of measures which assessed test-retest reliability, the median correlation coefficient was 0.71 and median Kappa was 0.51.(149) It should be noted that of 195 measures reviewed, only eight reported the test-retest reliability.(149) As an added point, only 6% of studies reported on content validity, construct or criterion validity, and reliability.(149) This study examined each of these as well as face validity, thus providing a thorough assessment of the psychometric properties of the developed measure.

In summary, the results of the psychometric testing were overall positive. Face validity, content validity, and construct validity were all acceptable. The measure demonstrated good internal consistency. Test-retest reliability was fair though not unacceptable. Further work is needed examining the measure with a broader population of caregivers than those who participated in this study. Additionally, further recruitment of persons living with dementia would be required in order to make conclusions about the measure with this population, though the limited results from this study are promising and encourage future work in this area.

Chapter 6 Summary and General Discussion

6.1. Summary

As was described throughout this dissertation, this research study consisted of three phases. The objective of Phase I was to conduct a thematic synthesis to develop a healthcare experiences model that would be utilized to identify possible measure domains. This led to Phase II which involved the consultation of persons living with dementia and caregivers to obtain feedback on the measure domains so as to refine the measure. In the third and final phase, the objective was to test the psychometric properties of the measure. The methodologies, results, and conclusions of each of these phases will be briefly summarized.

Phase I was a qualitative review of the literature pertaining to the healthcare experiences in primary and secondary care of persons living with dementia and their caregivers. Several electronic databases were searched and over 2900 records were screened by two reviewers. The final sample of included studies was 90. Study characteristics as well as qualitative data were extracted from each study. A thematic synthesis approach was used to analyze data and synthesize the results into a healthcare experiences model. The analysis resulted in eleven descriptive themes: diagnosis; time; communication; information; coordination of care; relationship with healthcare provider; supports and services; specialist and team-based care; role and identity; future; and positive experiences. From these descriptive themes, analytical themes were developed and organized into a healthcare experiences model as presented in Figure 7. These analytical themes formed the domains from which the measure items were developed. The thematic synthesis resulted in the development of one model encompassing experiences of both persons living with dementia and caregivers. Therefore, two versions of one measure were developed, differing only in wording of the instructions for persons living with dementia and caregivers. A decision was also made to focus the measure on the diagnostic healthcare experiences as opposed to all stages of the journey for reasons previously described. This measure of diagnostic healthcare experiences was presented to persons living with dementia and caregivers in Phase II in order to obtain their feedback.

Phase II utilized individual interviews, dyad interviews, and focus group interviews as a means of obtaining feedback from persons living with dementia and caregivers on the measure. Thirteen persons living with dementia and 16 caregivers participated. Interviews were audio recorded and transcribed. Memo notes were also written throughout the data collection process. Transcripts and memo notes were analyzed using inductive content analysis, separately for the individual interviews, dyad interviews, and focus group interviews. Five categories emerged from the content analysis, with all five categories emerging in the group interviews and different combinations of four of the five categories in the individual interviews and focus groups. The five categories were: sharing of lived experiences, feedback pertaining to the content of the questionnaire, feedback related to process of completing the questionnaire, participants' interests in next steps of the study, and interview/focus group experience. The sharing of lived experiences, participants' interests in next steps of the study, and the interview/focus group experiences categories provided an insight into how the data collection transpired and perhaps some insight into the participants themselves. The remaining categories of feedback pertaining to the content of the questionnaire and the process of completing the questionnaire were the main sources of suggested modifications to the measure. As a result of the feedback obtained from participants, major changes were made to the instructions of the measure. Wording changes were also made to some measure items as described in greater detail in section 4.3.3. An additional item was added regarding the missing topic of driving, which was brought up by participants. Participants were emailed a list of proposed modifications. No replies were received. The measure was modified according to the feedback obtained and finalized for psychometric testing in Phase III.

The psychometric testing conducted in Phase III consisted of assessments of face validity, content validity, construct validity, internal consistency, and test-retest reliability. Face validity was determined by asking participants to rate the suitability of the measure on a 5-point scale, while content validity was assessed through the completion of a content validity matrix. Construct validity was calculated by examining the correlation between scores on the measure with participants' responses on a single item asking them the degree to which the expectations of their healthcare experiences were met. Internal consistency was determined by calculating Cronbach's α and test-retest reliability was assessed by asking participants to complete the measure twice, two weeks apart. An ICC (2,1) was calculated. Eighteen caregivers and three persons living with dementia participated. Consequently, there were not enough participants in the persons living with dementia group to conduct sufficiently-powered statistical analyses. However, the caregiver group did reach the required sample size. Face validity and content validity were found to be good. Correlation with a global question on the degree to which healthcare expectations were met showed good construct validity (Spearman correlation coefficient of 0.71). Internal consistency was high (Cronbach's $\alpha = 0.78$). Test-retest reliability was fair. The ICC(2,1) was 0.62. While this could be improved, the results are similar to those of psychometric testing of other measures that have been developed for use with persons living with dementia and caregivers. Hypothesized reasons for the lower test-retest reliability were presented in section 5.4.

This dissertation will conclude with a discussion of the study in the context of the theoretical approach outlined in section 2.2.1, constructivist grounded theory. This will be followed by anticipated implications arising from this work, both in research and clinical settings. The overall limitations which must be considered when interpreting the results will also be described. Finally, avenues for future research directions will be discussed, followed by the final conclusions.

6.2. Application of constructivist grounded theory

Though each phase of the study built on the previous one, an overall theoretical approach to interpretation and analysis was selected in order to provide an additional layer of connection between phases. Constructivist grounded theory was determined to be most appropriate, for reasons presented in section 2.2.1. Constructivist grounded theory rejects the existence of an objective reality and acknowledges that multiple individual realities exist which are influenced by context.(20) This was the case throughout this research study, as it was acknowledged that each individual person living with dementia and their caregiver had his or her own reality of the dementia healthcare experience and that this in turn was shaped by the context in which the experience occurred. My position as researcher was to reconstruct these experiences and their meanings.(20)

In doing so, Kathy Charmaz, one of the main proponents of constructivist grounded theory, recommends that the researcher aim to maintain the voice of participants while still being analytical.(21, 22) The researcher should aim to evoke the participants' experiences.(21, 22) It is a balance to maintain the presence of participants' experiences in the final analysis and interpretations conceptualized by myself, the researcher.(22) This was a balance that I strove for throughout my presentation of results and analysis. For example, the model of healthcare experiences developed as a result of the thematic synthesis is a representation of my interpretation of the experience. However, this model arose from data provided by persons living with dementia and caregivers in the research literature. In my presentation of results, I aimed to show how the experiences of participants informed the nodes which were developed and ultimately the descriptive themes and analytical themes leading to the development of the model. This was done through presentation of direct quotes in support of the descriptive themes and by sharing a visual representation of how the nodes fit into the themes (Figure 6). By retracing the development of the model, one can see the role that participant voices play.

As was described above, one recommended method for maintaining the voice of participants within the analysis and interpretations is through the use of direct quotes from participants. This was done in both Phase I and Phase II. Direct quotes are presented throughout the results in Chapters 3 and 4. Phase I and Phase II were qualitative in nature, while Phase III was quantitative. However, through continuing to write memo notes in the quantitative phase, I was able to keep the voice of participants in the data and analysis. For example, when I was contemplating reasons for the low number of persons living with dementia participating in Phase III, a review of my memo notes resulted in quotes by caregiver participants that may have helped to explain this result (as presented in section 5.4). Similarly, when contemplating the results of test-retest reliability and reasons why the ICC may have been lower, a quote from a participant in Phase II stood out. The participant stated:

> “One of the things is, when you ask this, it depends on when you ask this, give this questionnaire, because if it’s right after your diagnosis has been made you’re pretty well reeling and uh I was trying to think back, it was three years ago so, you know I can’t even remember but I know that I was sort of like in a fog, in a daze.”

The voice of this participant helped in my interpretation of the statistical results and provided some insight as to why it may not have been as high as expected. In these ways, I aimed to balance the presence and voices of participants with my interpretations. Maintaining memo notes throughout all three phases and being cognizant of my reflexive standpoint helped me to acknowledge my role in co-creating and interpreting the realities and experience of participants, without losing sight of their voices as is the aim of constructivist grounded theory.

6.3. Implications

This work has implications in both research and clinical settings. Firstly, the model which was developed as a result of the thematic synthesis in Phase I may be useful to both researchers and clinicians in order to better understand the healthcare experiences of persons living with dementia and caregivers, based on their shared experiences reported in the literature. The model may serve to inform future research studies in this area and may also help healthcare providers identify the elements of the experience which are important to patients and caregivers throughout the stages of the healthcare experience.

With regard to research implications of the measure itself, the measure can be used to assess the effectiveness of interventions aimed at improving the diagnostic healthcare experiences of persons living with dementia and their caregivers. In order for researchers to be able to assess change, it is important to have a valid and reliable way in which to measure the experience. Currently, this is the only measure of this type which exists. Moreover, it has demonstrated strong validity and acceptable reliability. There has been considerable research and exploration of healthcare experiences of persons living with dementia and caregivers, particularly with regard to diagnosis.(7, 8) This was demonstrated in the Phase I thematic synthesis which was conducted. As the emphasis shifts from identifying challenges to focusing on the improvement of patient experience in healthcare in general (150), this is likely to also become the case with dementia healthcare experiences. This measure may have utility for researchers exploring the improvement of experiences.

The development of a measure of the healthcare experiences of persons living with dementia and caregivers also has implications from the perspective of healthcare organizations. Quality improvement is a key focus in healthcare.(150) The role that assessment of patients' experiences can play in quality improvement is increasingly being recognized. The Canadian Foundation for Healthcare Improvement published an article entitled: "What if patients' experiences guided quality improvement and organizational change?"(150) The author points out that patients are present for every step of their healthcare experience and possess the knowledge of their needs and preferences.(150) The patients, as experts of the healthcare experience, can provide feedback and the involvement of individuals in this way can create a more responsive system.(150) The measure developed and described throughout this dissertation can provide such a feedback mechanism.

In addition to creating a more responsive system, improving patient experience can have positive effects clinically. The Agency for Healthcare Research and Quality within the US Department of Health and Human Services has stated that in spite of competing priorities and limited resources, there is a strong clinical case for improving patient experiences.(151) Patient experience has been found to positively correlate with processes of care for disease management.(152) Patients' experiences communicating with providers have been found to correlate with adherence to medical advice and treatment, particularly among patients with chronic conditions.(153-156) The developed measure addresses communication as well as other important aspects of the healthcare experience which collectively can provide a picture of the healthcare experience. It may help to identify areas of the healthcare experience requiring improvement, allowing healthcare administrators to target these areas with quality improvement initiatives and potentially improve patient outcomes.

In Ontario, Health Quality Ontario offers numerous resources to healthcare providers to improve quality of care. One target area is primary care. An experience survey is available for download which can be used to measure patient experience in primary care.(157) The Health Quality Ontario website states: “Primary care providers can measure their patients’ experiences with the Primary Care Patient Experience Survey. Understanding patient perspectives can provide insight into current strengths and opportunities for improvement and inform the practice’s annual Quality Improvement Plan.”(157) Similarly, the developed measure of dementia diagnostic healthcare experiences may be used to identify strengths and opportunities for improvement. This may be of use to healthcare providers in primary and secondary care, including in memory clinics and specialized teams such as geriatric outreach teams.

In summary, there is a need in both research settings and clinical environments for a measure of dementia healthcare experience. In research settings, the measure provides a validated and fairly reliable assessment of experience which is necessary for determining the effectiveness of interventions. From the perspective of healthcare providers and organizations, the measure may be used to guide quality improvement initiatives, thereby improving patient experiences and potentially clinical outcomes.

6.4. Limitations

Overall, there were many strengths to the study which was conducted. However, there were also limitations which must be considered when interpreting the results. Though these have been described in detail within each chapter as appropriate, it is worth reviewing the main limitations before presenting the final conclusions in this dissertation. Phase I and Phase II involved the analysis of a large amount of qualitative data. In each phase, the qualitative analyses (thematic synthesis and inductive content analysis) were only conducted by myself. The methodological rigour of these analyses could have been improved with the involvement of another researcher in the analyses. This would have helped to mitigate any inherent biases I may have had due to my own experiences and perspective. An attempt was made to minimize these biases through reflexivity and acknowledgement that these exist.

In addition to review by another researcher, the resulting model which was developed in Phase I could have benefited from greater review by persons living with dementia and caregivers. Though the model was presented to participants in the interviews and focus groups conducted in Phase II, the topics of discussion focused on the developed measure. Therefore, participants did not share any comments or thoughts on the model, aside from at most nodding as they reviewed it. Consequently, the model should be viewed with the knowledge that it is informed by the experiences of persons living with dementia and their caregivers as presented in the research literature, rather than through feedback obtained on the model.

A common limitation to Phases II and III was that of the source of participants and consequently the generalizability of results. As was discussed, the Alzheimer Society was relied on heavily for recruitment purposes. This limited the population from which participants were drawn and it is likely that this group differs from other persons living with dementia and caregivers who have not made contact with the Alzheimer Society. Moreover, caregivers who participated in Phase II and III were all either children or spouses of persons living with dementia. Views of other types of informal caregivers were not obtained. Experiences of participants were limited to only certain types of dementia. There was also a lack of ethnic diversity amongst participants. The results of this study can only be applied to populations with similar characteristics. For this reason, the characteristics of participants in Phase II and Phase III were described in detail in sections 4.3.1 and 5.3.1 respectively. Results and conclusions should be interpreted with these characteristics in mind.

Finally, though a considerable number of persons living with dementia participated in Phase II, recruiting more persons living with dementia for participation in Phase III proved to be a challenge. Several caregivers shared that their parent or spouse was simply not capable of participating. Moreover, many of the persons living with dementia who attend the support groups at the Alzheimer Society for individuals with early stage disease, which was a main source of participants in Phase II, were enrolled in an art program through the Alzheimer Society. Participation in one more thing was too much for many individuals. Recruiting individuals from the community was even more challenging than through the Alzheimer society. Due to the low number of participants in the persons living with dementia group, it was not possible to draw conclusions about the validity and reliability of the measure with this group. However, preliminary results were encouraging of pursuing further work with persons living with dementia. This as well as other future research directions stemming from this thesis work are presented in the section which follows.

6.5. Future research directions

There are several avenues that a future program of research could take based on the results of this work. As was described, further research is needed with persons living with dementia due to the limited number of participants in Phase III in order to be able to make conclusions regarding the validity and reliability of the measure with this population. Though validity and reliability were assessed in the caregiver population, future work with a more varied group of participants would also be beneficial. This would improve the generalizability of the measure.

Prior to commencement of the study, it was anticipated that the measure would cover all stages of the healthcare experience. Following the development of the healthcare experiences model in Phase I, it was determined that such a measure would be too broad. A decision was made to focus on the healthcare experiences of obtaining and receiving a diagnosis. Consequently, there is potential to develop measures for the remaining two stages identified in the model: living with dementia; planning for the future. A measure developed for each of these stages could undergo the same processes of review and feedback from persons living with dementia and caregivers such as in Phase II and psychometric testing such as in Phase III. These three measures could potentially form a series of measures which could be used for assessing the healthcare experiences of persons living with dementia and their caregivers.

The developed measure also focused solely on experiences with physicians as the healthcare providers on which participants were to base their responses. This was because physicians are ultimately the individuals who make the diagnosis. However, measures could also be developed for the other healthcare providers who may be involved, such as nurses, and the role these individuals play in the experience. Team-based care is becoming increasingly common and it may be valuable to explore the development of similar measures with other types of healthcare providers commonly found on such teams.

6.6. Conclusions

This dissertation has presented the development and psychometric testing of a measure of the healthcare experiences of persons living with dementia and caregivers when obtaining and receiving a diagnosis. A model of dementia healthcare experiences was developed, from which the measure was drafted. Through the feedback of persons living with dementia and caregivers, the measure was revised. The revised measure underwent psychometric testing with overall positive results, however these analyses were limited to data from caregivers as an insufficient number of persons living with dementia participated in this phase of the project. Nevertheless, the development of such a measure fills an existing gap in this area of research of healthcare experiences of persons living with dementia and caregivers and may be useful to both researchers conducting future studies as well as healthcare providers and organizations aiming to improve quality of care and patient healthcare experiences. Future work may focus on further testing of the measure with persons living with dementia, as well as developing similar measures for other stages of the dementia healthcare experience.

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Appendix 1: Search Strategy

MedLINE/EMBASE

1. Primary Health Care/

2. Primary Care Nursing/ or Nurse Practitioners/

3. Physicians, Family/ or Physicians, Primary Care/

4. General Practitioners/ or Family Practice/

5. exp General Practice/

6. Community Psychiatry/ or Geriatric Psychiatry/

7. Nurse Clinicians/

8. Nurses, Community Health/

9. Nurses, Public Health/

10. Pharmacists/

11. Geriatrics/

12. Psychiatric Nursing/

13. Social Workers/

14. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13

15. exp Dementia/

16. Alzheimer Disease/

17. 15 or 16

18. (interview: or experience:).mp. or qualitative.tw.

19. ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)) or

(focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")).ti,ab. or interviews as topic/ or focus groups/ or narration/ or qualitative research/

20. Nurse-Patient Relations/

21. exp Physician-Patient Relations/ or Patient Satisfaction/

22. (experience* or view* or opinion* or perspective*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

23. 20 or 21 or 22

24. 14 and 17 and 18 and 23

25. limit 24 to english language

26. 14 and 17 and 19 and 23

27. limit 26 to english language

28. dementia.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

29. alzheimer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

30. 28 or 29

31. 17 or 30

32. 14 and 23 and 31

33. limit 32 to english language

34. family pract*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

35. general pract*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

36. primary care*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

37. secondary care*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

38. family physician.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

39. psychiatr*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

40. 14 or 34 or 35 or 36 or 37 or 38 or 39

41. 18 and 32

42. limit 41 to english language

43. 19 and 32

44. limit 43 to english language

45. 18 and 23 and 31 and 40

46. limit 45 to english language

47. 19 and 23 and 31 and 40

48. limit 47 to english language

PsycINFO

((Index Terms:("Client Satisfaction") OR Index Terms:("Consumer Satisfaction")) OR Any Field:(Experience* OR view* OR opinion* OR perspective*)) AND

(Any Field:(experiences OR interview OR qualitative)) AND

((Index Terms:("Alzheimer's Disease") OR Index Terms:("Dementia")) OR Any Field:(Dementia OR Alzheimer*)) AND

((Index Terms:("Clinicians") OR Index Terms:("Community Psychiatry") OR Index Terms:("Family Medicine") OR Index Terms:("Family Physicians") OR Index Terms:("General Practitioners") OR Index Terms:("Geriatrics") OR Index Terms:("Nurses") OR Index Terms:("Pharmacists") OR Index Terms:("Primary Health Care") OR Index Terms:("Psychiatrists") OR Index Terms:("Social Workers")) OR Any Field:(family pract* OR general pract* OR primary care* OR secondary care* OR family physician OR psychiatr*))

CINAHL

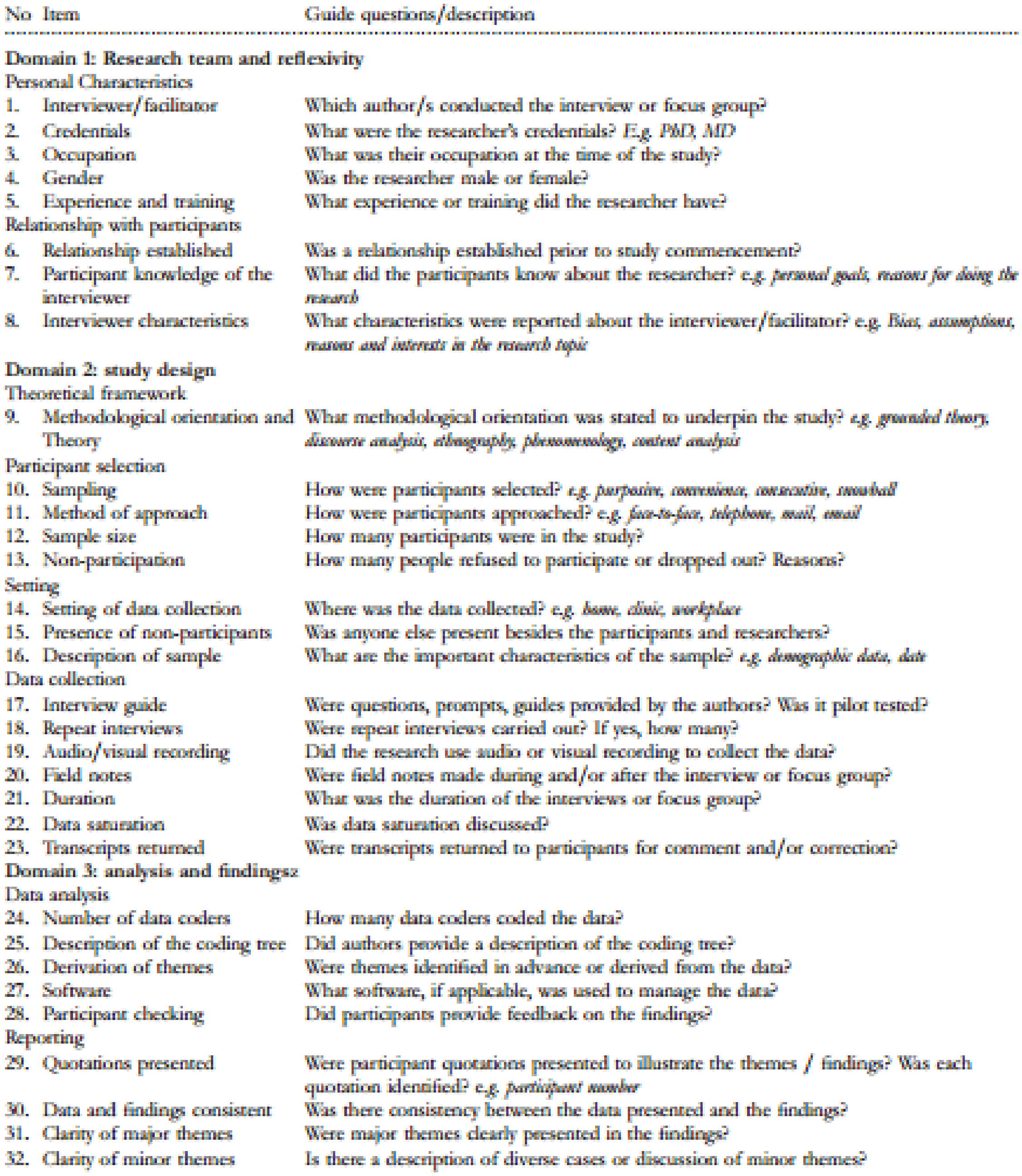
((MH ((MH "Primary Health Care") OR (MH "Secondary Health Care") OR (MH "Physicians, Family") OR (MH "Geriatricians") OR (MH "Psychiatrists") OR (MH "Family Practice") OR (MH "Psychiatry") OR (MH "Geriatric Psychiatry") OR (MH "Nurses by Role") OR (MH "Gerontologic Nurse Practitioners") OR (MH "Practical Nurses") OR (MH "Geriatrics") OR (MH "Pharmacists") OR (MH "Social Work, Psychiatric") OR (MH "Social Work"))) OR (TX (family pract* OR general pract* OR primary care* OR secondary care* OR family physician OR psychiatr*))) AND

((MH ((MH "Dementia+") OR (MH "Alzheimer's Disease"))) OR (TX (Dementia OR Alzheimer*))) AND

((MH ((MH "Consumer Satisfaction") OR (MH "Patient Satisfaction"))) OR (TX (Experience* OR view* OR opinion* OR perspective*))) AND

(TX "interview" OR MH "audiorecording" OR qualitative stud*)

Appendix 2: Consolidated criteria for reporting qualitative research (COREQ)(30)



No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *e.g. participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Appendix 3: Guidelines for enhancing transparency in reporting the synthesis of qualitative research(75)

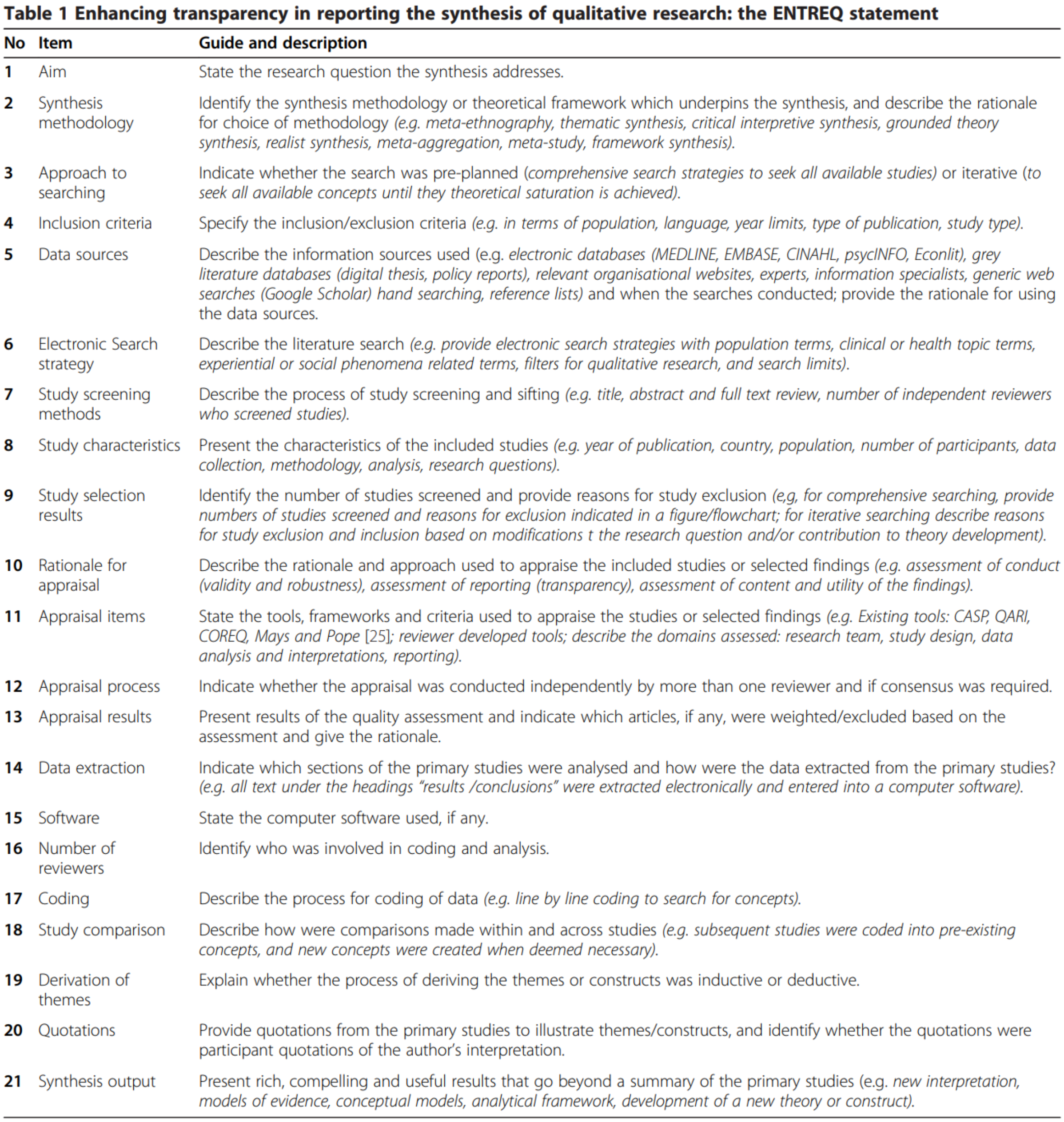


Table 1 Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement

No	Item	Guide and description
1	Aim	State the research question the synthesis addresses.
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*
3	Approach to searching	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved).*
4	Inclusion criteria	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).*
5	Data sources	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.
6	Electronic Search strategy	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).*
7	Study screening methods	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*
8	Study characteristics	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope* [25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).*
15	Software	State the computer software used, if any.
16	Number of reviewers	Identify who was involved in coding and analysis.
17	Coding	Describe the process for coding of data *(e.g. line by line coding to search for concepts).*
18	Study comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*

Appendix 4: Draft dementia healthcare experiences questionnaire (person living with dementia version)

DEMENTIA HEALTHCARE EXPERIENCE QUESTIONNAIRE

Please think back to the appointment where you received your diagnosis from your physician.

Base your answers to the following questions on this appointment and indicate your answers by circling the appropriate response. Thank you!

1. The wait time for an available appointment was reasonable.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

2. The appointment was rushed.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

3. The physician communicated clearly with me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

4. The physician explained test results to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

5. I was treated respectfully during the appointment.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

6. I was able to ask any questions I may have had at the time.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

7. The physician provided me with a reasonable amount of information.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

8. The physician provided me with information that was relevant to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

9. The physician offered information which could help me maintain my current lifestyle.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

10. I knew how to obtain support if needed following this appointment.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

11. The healthcare provider I am referring to is a (please check):

☐ Family physician
☐ Psychiatrist
☐ Geriatrician
☐ Neurologist
☐ Other: _____________________

12.Please share any additional comments you may have.

____

____

____

____

____

Appendix 5: Draft dementia healthcare experiences measure (caregiver version)

DEMENTIA HEALTHCARE EXPERIENCE QUESTIONNAIRE

Please think back to the appointment where your family member or friend received his/her diagnosis from his/her physician.

Base your answers to the following questions on this appointment and indicate your answers by circling the appropriate response. Thank you!

1. The wait time for an available appointment was reasonable.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

2. The appointment was rushed.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

3. The physician communicated clearly with me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

4. The physician explained test results to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

5. I was treated respectfully during the appointment.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

6. I was able to ask any questions I may have had at the time.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

7. The physician provided me with a reasonable amount of information.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

8. The physician provided me with information that was relevant to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

9. The physician offered information which could help me maintain my current lifestyle.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

10. I knew how to obtain support if needed following this appointment.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

11. The healthcare provider I am referring to is a (please check):

☐ Family physician
☐ Psychiatrist
☐ Geriatrician
☐ Neurologist
☐ Other: ______________________

12.Please share any additional comments you may have.

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Appendix 6: Information letter and consent form

University of Waterloo

Title of Project: ***Development and psychometric testing of a measure of the healthcare experiences of persons with dementia and their caregivers***

Organizers*:* ***Jeanette Prorok & Dr. Paul Stolee***
University of Waterloo, School of Public Health and Health Systems
613-449-7133

This session focuses on obtaining feedback on a measure of healthcare experience for persons with dementia and their caregivers and will be facilitated by Jeanette Prorok. This study is being conducted as part of Jeanette's doctoral thesis work.

Participation in this session is voluntary and involves approximately 60 minutes of your time to participate in a discussion soliciting your feedback on a measure which has been developed for assessing the healthcare experiences of persons with dementia and their caregivers. You will also be asked to complete a demographic questionnaire, which will ask questions such as your gender, living arrangements, marital status, and income range. There are no known or anticipated risks to your participation in this session. You may decline answering any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. The session will be audio recorded with your permission and transcribed. All information you provide will be considered confidential and grouped with responses from other participants. Your name will not be identified with the input you give to this session. Further, you will not be identified by name in the report that the facilitator produces for this session. The information collected from this session will be kept for a period of seven years in a locked filing cabinet in Jeanette Prorok's office.

Given the group format of this session we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#21692). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions contact Jeanette Prorok at jcprorok@uwaterloo.ca or 613-449-7133.

Thank you for your assistance with this project. In appreciation of your time given to this session we will provide you with a $30 Tim Horton's gift card. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

Yours sincerely,

Jeanette Prorok

Consent of Participant

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Jeanette Prorok of the School of Public Health and Health Systems at the University of Waterloo under the supervision of Dr. Paul Stolee. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time by advising the researchers of this decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#21692). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.
For all other questions contact Jeanette Prorok at jcprorok@uwaterloo.ca or 613-449-7133.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name

Signature of Participant

Dated at

Witnessed

Appendix 7: Demographic questionnaire (person living with dementia version)

ID # (filled in by Jeanette): ______ Age: ______________

Gender: ☐ Male ☐ Female ☐ Other: ______________________

Current Living Situation:

☐ Alone

☐ With spouse

☐ With other family members

☐ With non-family members

☐ Other. Please specify: ____

Highest level of education completed:

☐ Elementary school

☐ High school

☐ College

☐ University degree

☐ Post-graduate degree

Marital Status:

☐ Single

☐ Married or Common Law

☐ Widowed

☐ Divorced

Annual household income:

☐ $0-$24 999

☐ $25 000- $49 999

☐ $50 000- $74 999

☐ $75 000- $99 999

☐ $100 000+

Appendix 8: Demographic questionnaire (caregiver version)

ID # (filled in by Jeanette): ______ Age: ________

Gender: ☐ Male ☐ Female ☐ Other: ____________________

Relationship to Person with Dementia:

- ☐ Spouse
- ☐ Child
- ☐ Sibling
- ☐ Friend
- ☐ Other:____

Highest level of education completed:

- ☐ Elementary school
- ☐ High school
- ☐ College
- ☐ University degree
- ☐ Post-graduate degree

Marital Status:

☐ Single

☐ Married or Common Law

☐ Widowed

☐ Divorced

Annual household income:

☐ $0-$24 999

☐ $25 000- $49 999

☐ $50 000- $74 999

☐ $75 000- $99 999

☐ $100 000+

Appendix 9: Interview guide

1) What are your first thoughts about this questionnaire?

2) What do you like about this questionnaire?

3) What don’t you like about this questionnaire?

4) Is there anything you feel that should be covered by this questionnaire but is not?

5) Is there anything which you feel should be removed?

6) If you could change something about this questionnaire, what would it be?

7) How easy do you find the questions to understand?

8) Would you change any of the words used in this questionnaire?

9) Do you find the questionnaire to be easy to read (in terms of font type, size, spacing, etc)?

10) Do you have any other comments you would like to share pertaining to the questionnaire?

Appendix 10: Revised dementia healthcare experience questionnaire (person living with dementia version)

DEMENTIA HEALTHCARE EXPERIENCE QUESTIONNAIRE

Please think back to the appointment where you received your diagnosis from your doctor.

The doctor who delivered the diagnosis was a (please check):

☐ Family doctor
☐ Psychiatrist
☐ Geriatrician
☐ Neurologist
☐ Other: ________________________
☐ Uncertain

The diagnosis was made in a (please check):

☐ Family doctor's office
☐ Memory clinic
☐ Hospital
☐ Other: ________________________
☐ Uncertain

If you wish, you may share any additional details regarding the appointment at which the diagnosis was made.

____
____
____
____
____

Base your answers to the following questions **on the appointment which you described above** and indicate your answers by <u>circling</u> the appropriate response. Thank you!

1. The wait time for an available appointment was reasonable.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

2. The appointment was rushed.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

3. The doctor communicated clearly with me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

4. The doctor explained test results to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

5. I was treated respectfully during the appointment.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

6. I was able to ask any questions I may have had at the time.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

7. The doctor provided me with a reasonable amount of information.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

8. The doctor provided me with information that was relevant to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

9. The doctor offered information which could help me improve my current lifestyle.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

10. I was given information about available supports and services.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

11. The doctor approached the topic of driving with sensitivity.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

12. Please share any additional comments you may have.

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Appendix 11: Revised dementia healthcare experience questionnaire (caregiver version)

DEMENTIA HEALTHCARE EXPERIENCE QUESTIONNAIRE

Please think back to the appointment where your family member or friend received his/her diagnosis from his/her doctor.

The doctor who delivered the diagnosis was a (please check):

☐ Family doctor
☐ Psychiatrist
☐ Geriatrician
☐ Neurologist
☐ Other: ________________________
☐ Uncertain

The diagnosis was made in a (please check):

☐ Family doctor's office
☐ Memory clinic
☐ Hospital
☐ Other: ________________________
☐ Uncertain

If you wish, you may share any additional details regarding the appointment at which the diagnosis was made.

____
____
____
____
____

Base your answers to the following questions **on the appointment which you described above** and indicate your answers by circling the appropriate response. Thank you!

1. The wait time for an available appointment was reasonable.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

2. The appointment was rushed.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

3. The doctor communicated clearly with me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

4. The doctor explained test results to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

5. I was treated respectfully during the appointment.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

6. I was able to ask any questions I may have had at the time.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

7. The doctor provided me with a reasonable amount of information.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

8. The doctor provided me with information that was relevant to me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

9. The doctor offered information which could help me improve my current lifestyle.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

10. I was given information about available supports and services.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

11. The doctor approached the topic of driving with sensitivity.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not applicable/ Uncertain

12. Please share any additional comments you may have.

____

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